

**Self Help in the electronic age: an evaluative study of  
actual and potential uses of the Internet to support  
self help groups and their development agencies**

**by**

**Matthew John Clements, M.A. (Cantab.)**

**A Master's Dissertation, submitted in partial  
fulfilment of the requirements for the award of  
Master of Science degree of Loughborough University.**

**September 1997**

**Supervisor: Janet Rolinson, BA, MHSM, DipHSM  
Department of Information and Library Studies**

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## Abstract

This research sets out to evaluate the applicability of several aspects of the Internet to self help activity, with special reference to Self Help Nottingham (a local umbrella organisation for self help groups whose national profile for self help research and promotion provides an additional focus.)

This evaluation centres on three key levels: the use of online self help and support groups; the development of an electronic "clearinghouse" model to disseminate information, promote self help approaches to health and social care professionals, and serve as a resource for groups; and the use of the Internet to gather information on self help issues, conduct research and evaluate examples of current best practice.

Key characteristics of self help activity are delineated, and the wider context of IT implementation in the voluntary sector used to illustrate the strategic information needs of small-scale, non-commercial organisations.

A portfolio of methodological approaches include an Internet-based literature review, a case study of an issue-specific online support/discussion list (using a form of content analysis) and a series of evaluative case studies of North American and UK self help and voluntary sector WWW sites. The advantages and disadvantages of online group dynamics are examined, and comparisons drawn between UK and US interpretations.

The WWW case studies, together with the local and national contexts within which Self Help Nottingham operates, provide the background for the development of a working WWW resource site, incorporating locally-derived information and evaluated Internet resources. The site design process is described, and content and quality issues are examined. Guidelines for the evaluation of Internet material are set out, and recommendations made for the ongoing development of the site.

The WWW clearinghouse model offers the potential to develop Internet-based services to self help groups and professionals, adapted to fit the UK consumer healthcare context, at the same time addressing issues of policy formation and research at a national level.

## Acknowledgements

*No man is an Island, entire of itself;  
every man is a piece of the Continent, a part of the main.*

John Donne [Devotions, XVII]

*When it was proclaimed that the library contained all books, the first impression was one of extravagant happiness. All men felt themselves to be the masters of an intact and secret treasure. There was no personal or world problem whose eloquent solution did not exist in some hexagon.*

Jorge Luis Borges [The Library of Babel]

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I should like to take this opportunity to extend my appreciation:

to my supervisor Janet Rolinson, for her encouragement and support throughout the academic year,

to Nicki Hastie and the staff at Self Help Nottingham, for initiating this research project and providing the focus for many of its findings,

to my family, for their unswerving faith, infinite patience and unquenchable good humour,

and to Gery, for her strength and understanding, *mijn geduldigste onderwijzeres*.

## Contents

<b>Abstract</b>	ii
<b>Acknowledgements</b>	iii
<b>Contents</b>	iv
<b>List of figures</b>	viii
<b>List of tables</b>	viii
 <b>Chapter 1: Introduction</b>	
1.1. Self help and the Internet: Convergence or Contradiction?	1
1.2. Aims and Objectives	2
1.3. Approach	5
1.4. Methodologies	5
References	7
 <b>Chapter 2: Defining Self-Help Activity</b>	
2.1. Introduction	9
2.2. An explanatory framework	10
2.3. What Self Help is not...	10
2.4. Literature review	10
2.5. Key Principles	13
2.5.1. Mutuality	13
2.5.2. Shared Experience	13
2.5.3. Self-determination & Group ownership	14
2.5.4. Active Participation & Serial Reciprocity	14
2.6. Types of self help activity	15
2.6.1. Issue specific groups	15
2.6.2. Community Development	15
2.6.3. Psychotherapeutic Self Help	15
References	16
 <b>Chapter 3: Self Help Groups and Electronic Communication</b>	
3.1. Introduction	18
3.2. Methodology	18
3.3. Sources	18
3.4. Internet Problematics	19
3.5. Accounts of Electronic Self Help Activity	20
3.5.1. Issues of Evolution and Equivalence	20
3.5.2. Internet accounts	21
3.5.3. Journalistic accounts	24
3.5.4. Academic-related accounts	25
3.6. Discussion and Analysis	28
3.7. Advantages	28
3.7.1. Wider access to meetings	28
3.7.2. Diffusing Dependency	29
3.7.3. Reducing the Isolation of Rarity	29
3.7.4. Reducing barriers based on social status cues	29
3.7.5. The Realities of Access	30
3.7.6. Internet demographics	30
3.7.7. Encouraging Participation and Promoting Communication	32
3.7.8. Training for Professionals and Group Leaders	33
3.8. Disadvantages	34

3.8.1. Destructive interactions	34
3.8.2. Leadership issues	34
3.8.3. Promoting social isolation	35
3.8.4. Identity and Communication	35
References	36
 <b>Chapter 4: Online Self Help Group Case Study</b>	
4.1. Methodology: Narrative Theory as Conceptual Framework	43
4.2. Content Analysis	43
4.3. Limitations	44
4.4. Case Study - List Demographics	45
4.5. Frequency of Postings	46
4.6. List Disclaimers Concerning Information Content	48
4.7. Categories of Content Analysis	48
4.7.1. Broad Categories	48
4.7.2. Narrative accounts	49
4.7.3. Information Requests	50
4.7.4. Information Responses	51
4.7.5. List Management Issues	53
4.7.6. Off-Topic Discussions	53
4.8. Conclusion	54
References	54
 <b>Chapter 5: Self Help and the UK Consumer Health Context</b>	
5.1. Introduction	55
5.2. The role of Professionals: collaboration, cooperation or co-option?	55
5.3. National policy: vacuum or opportunity?	56
5.4. A national voice for self help?	58
References	58
 <b>Chapter 6: Self Help Nottingham - The Project Partners</b>	
6.1. Background	60
6.2. Information audit	60
References	61
 <b>Chapter 7: Implementation of IT in the Voluntary Sector</b>	
7.1. The Voluntary Sector Context	62
7.2. Generalised stage hypothesis	63
7.3. Self Help Nottingham IT Inventory	64
7.4. Potential for Cooperation	65
References	65
 <b>Chapter 8: The Self Help Clearinghouse Model</b>	
8.1. Context	66
8.2. The electronic clearinghouse: early approaches	67
References	68
 <b>Chapter 9: Evaluative Case Studies of WWW Sites - UK</b>	
9.1. Northern Advisory Group on Disability	70
9.2. HEBSWEB	74
9.3. National Institute for Social Work	75
9.4. UK Primary Care	77

9.5. National Council for Voluntary Organisations	78
9.6. Help for Health Trust	79
9.7. Cambridgeshire County Council: Community Information Database	80
References	80
 <b>Chapter 10: Evaluative Case Studies of WWW Sites - North America</b>	
10.1. Self Help Network of Kansas	82
10.2. American Self Help Clearinghouse	84
10.3. Illinois Self-Help Coalition: Support Group Directory Online	87
10.4. Other US and Canadian Clearinghouses	88
10.5. Support-Group.com	88
10.6. Other Resources	89
References	90
 <b>Chapter 11: World Wide Web Resource Site: Design &amp; Implementation</b>	
11.1. Overall Aims	92
11.2. Background	92
11.3. Marketing Issues	93
11.4. Technical Aspects	93
11.5. Graphic Content	94
11.6. File Structure	95
11.7. Site Architecture	95
11.8. Site Content	96
11.8.1. Home Page	96
11.8.2. Overview	96
11.8.3. Contact Us	96
11.8.4. Directory	96
11.8.5. Groups	97
11.8.6. Posters	97
11.8.7. Professionals	97
11.8.8. Publications	98
11.8.9. Training	98
11.8.10. Forum	98
11.8.11. Organisations	98
11.8.12. Resources	99
11.8.13. Site Sponsors	102
11.8.14. News	102
11.8.15. National Directory	102
11.9. Full-text sources: costs and benefits	102
11.10. Legal and Ethical Issues	103
11.10.1. Specific Legislation	103
11.11. Evaluation	104
11.12. Recommendations	105
References	106
 <b>Chapter 12: Guidelines for the Evaluation of Internet Resources</b>	
12.1. Internet Problematics	108
12.2. Universal Directories and Search Engines	108
12.3. Reviewing the Reviewers	108
12.4. Guidelines	109
12.5. Core standards	110

References	110
<b>Chapter 13: Conclusion and Recommendations</b>	
13.1. Overall	111
13.2. Strategic issues	111
13.3. Online self help groups	112
13.4. Site development issues	114
13.5. Final word	115
References	115
<b>Bibliography</b>	
Print Sources	116
Electronic Sources	125
<b>Appendix</b>	
Print-outs of Self Help Nottingham WWW Resource Site screens	

## List of Figures

Figure 1.1.	Wilson's Model of Information Seeking Behaviour	6
Figure 4.1.	Total postings to group per month	46
Figure 4.2.	Frequent posters to group	47
Figure 4.3.	Broad content categories	49
Figure 4.4.	Types of information response	51
Figure 7.1.	Boyle et al's redefinition of Porter's 5 forces model for the social profit sector	62
Figure 9.1.	NAGD: Home Page	70
Figure 9.2.	NAGD: Alphabetical Group Listing	71
Figure 9.3.	NAGD: Single Record Display	72
Figure 9.4.	HEBSWEB: Support Group Database Display	75
Figure 9.5.	National Institute of Social Work: Full Text Resources	76
Figure 9.6.	UKPrimary Care: Address List of Self Help and Advice Agencies	78
Figure 9.7.	NCVO: Home Page	79
Figure 9.8.	Help for Health Trust: Home Page	79
Figure 9.9.	Cambridgeshire County Council: Community Information Database	80
Figure 10.1.	Self Help Network of Kansas: Index	82
Figure 10.2.	Self Help Network of Kansas: Resources for Groups	83
Figure 10.3.	Self Help Network of Kansas: Effectiveness of Groups	84
Figure 10.4.	Self Help Sourcebook Online: Home Page	85
Figure 10.5.	Self Help Sourcebook Online: Starting an on-line self help group	86
Figure 10.6.	Illinois Self Help Coalition: Home Page	87
Figure 10.7.	Example of full-text self help report material	88
Figure 10.8.	Support-group.com: Index	89
Figure 10.9.	Support-group.com: types of resource	90
Figure 11.1.	Web Resource Architecture [overview]	95
Figure 11.2.	Sample NLM PubMed Search: Results Display	99
Figure 11.3.	NHS Confederation Gateway	100
Figure 11.4.	Charities Aid Foundation's "CharityNet"	101

## List of Tables

Table 4.1.	Frequent posters to group	46
Table 4.2.	Broad content categories	48
Table 4.3.	Types of narrative content	50
Table 4.4.	Types of response	51



## Chapter 1: Introduction

*Help from without is often enfeebling in its effects, but help from within invariably invigorates*

Samuel Smiles

### 1.1. Self help and the Internet: Convergence or Contradiction?

Self help is a phenomenon whose precise shape is as difficult to discern as the Internet is to map with any degree of scientific confidence. Both are characterised by their fluctuating, often fragile and idiosyncratic qualities. Both can be seen as social movements sharing a common thread, that of *connection*. Both have claims made about their social value, their potential impact on the political and social fabric being the subject, to varying degrees, of an enthusiastic championing that often verges on the fanatical. In many ways, both refute concrete definition and all-embracing attempts at objective study or meta-analysis, shifting in shape and emphasis: at the very moment one senses clarity is within reach, the image blurs. Both self help and the Internet are self-perpetuating communities, the personal interwoven with the public, the whole greater than the sum of its parts.

Self help connects individuals in supportive networks centred on shared experiences. Self help is a particular form of support, located at one end of the health or social care continuum, grassroots in emphasis and non-authoritarian in tone. Self help is what its members believe it to be, refusing to fit into watertight definitions of how it should operate, its informality conferring benefits not found in traditional professional approaches. Self-determination is central to the self help coping process.

These themes strongly reflect those aspects of the Internet that are social and personal: connectivity, the development of networks of individuals and groups, the sharing of information, issues of openness and accessibility. No claim is too extravagant for those who proclaim its potential for enriching our lives and our work, its scope for the building of communities and empowering their members.

Could these two movements converge in some purposeful way, bringing benefits beyond the traditional face-to-face self help encounter and encouraging its promotion on the wider stage of health and social policy? Does the medium fit the message, or is something lost in the electronic

process? If self help is to become a cornerstone of the 21st century welfare state, an understanding of developments within the wider "information society" is crucial.

## 1.2. Aims and Objectives

This research project represents a commitment by Self Help Nottingham, an umbrella organisation for local self help groups, to begin to explore these themes and set an agenda for their wider information strategy. Their initial brief in March, later shaped by technical practicalities, initial findings and the limited timeframe, nevertheless outlines the area to be covered:

- working with the team to develop strategies for Internet use both internally and to extend online services and access to local self help groups: to be examined within a context of "good practice"
- searching the Internet to identify sites of relevance to self help groups and...development agencies
- research into how the Internet is used by individuals and groups as a source for therapy and personal support (through e-mail and Usenet discussion lists)
- evaluating self help information and support on the WWW, particularly in the UK, and through comparison with activities in the US and Canada

It became apparent that any one of these broad aims would provide sufficient possibilities for research at this level: electronic discussion lists exist for practically every condition covered in the Self Help Nottingham directory of local groups. "Access to groups" issues would similarly occupy a sizeable research project on community information.

This project attempts to address all four aspects and to provide an evaluative overview of current developments, prevailing trends and dominant attitudes, utilising a portfolio of research methodologies to explore and analyse the different levels and concepts in operation.

An overall aim can be stated:

to evaluate the use [both actual and potential] of the Internet by self help groups and their support agencies

In framing more specific research questions, a tripartite structure became apparent:

- the use of the Internet by *groups or individuals*, concentrating on the online or electronic support group phenomenon.
- the use of the Internet by *self help support agencies* to *promote* self help support and development at local, national and international level, through the development of a WWW Resource Site and allied services. [focused on dissemination and the foundation of networks]
- the use of the Internet by *self help support agencies* to *obtain* information on current developments in the field and to develop a portfolio of research resources to enhance the agency's information function [focused on the internal strategic use of Internet sources]

Because Self Help Nottingham were unable to access the Internet until late in the research timeframe, the involvement of local groups in any research was necessarily precluded. The WWW Resource Site developed significantly as the project progressed, focusing on both internal organisational information strategy and the "external" communication potential of the WWW (notwithstanding the fact that this represents the researcher's first encounter with HTML). This WWW focus in itself represents a necessary simplification of the term "Internet" throughout the project, since it omits USENET, ftp, telnet and other aspects. The Web's graphical user interface enables its applications to be more easily grasped for those with little or no experience of the Internet, and so proved a more tangible and realistic focus for the strategic aims of the project.

The question of online support groups was addressed by an analytical literature review, a wide-ranging evaluative survey of Internet materials, and the adoption of a modified content analysis/monitoring case study of a specific support group over a period of months (as a subscriber to the list and through access to archived postings.)

Within this overarching framework, more specific aims can be set out:

- to describe key characteristics of self help activity as a precondition of evaluating the ways in which the Internet can support it (as a medium both for the exchange of experiential knowledge/emotional support by individuals, and for its promotion by support agencies)
- to describe the UK consumer health/social care context as a means of identifying those agencies and professionals allied to self help who can then be targeted as information providers, facilitators

and resources through Internet strategies (e.g links to and from sites, dissemination and exchange of information, forums for policy discussion)

- to analyse self help support in the UK, the need for national developments, the concept of a UK “centre of excellence” and issues of promotion and partnership
- to describe the Self Help Nottingham organisation, in particular those roles and functions that could potentially be furthered by Internet strategies, and to outline the practicalities of involving support staff and self help groups in Internet use
- to evaluate the concept of an electronic *self help clearinghouse*, charting the development of US activity through a comparative analysis of UK and North American WWW sites, elucidating the key principles and contrasting US models with the practicalities of UK self help support
- examine issues of Internet marketing and promotion
- to develop a working model of a self help WWW site that demonstrates in practice the issues evaluated above [organisation of resources, evaluation of good/bad practice, “critical thinking” about Internet information etc.]
- to examine the use of e-mail discussion groups by self helpers; to delineate prevailing trends on the psychology of virtual communities as they relate to self help; to critically examine the literature published in this field; to examine ethical issues in research methodology; and to conduct a small-scale content analysis of a single online support group
- to describe and evaluate those Internet research tools most applicable to self help support agencies within the process of site design and to examine issues of quality
- to outline the wider theoretical context of the implementation of IT in the voluntary sector, and to outline resourcing implications for Self Help Nottingham
- to provide guidelines on assessing the quality of Internet sources
- to make recommendations for the future development of the WWW site and integration with IT strategy

### 1.3. Approach

It is of fundamental importance to note that Self Help Nottingham's commitment to developing an Internet strategy was manifest by their intention to acquire the necessary hardware *before* the project was initiated. However, the concrete timing of this acquisition fell originally outside the timeframe for the project, so limiting the initial framing of any participative research or evaluation.

When Internet access did arrive ahead of schedule, it was decided to develop a working model of a World Wide Web resource to give focus to many of the issues surrounding the introduction of the Internet to the work of the team. The focus of the research project of necessity shifted towards the role the Internet could play in the support of self help activity and development, since it offered the opportunity to articulate, through a working site model, the team's intention to develop a national profile for self help and serve as a "centre of excellence" and resource for self help research.

The style and strategy of the research design must be appropriate to the scale, culture and philosophy of the central case study. It was important that the group should not feel a solution or set of recommendations were being imposed from an outside, academic perspective without reference to their mode of operation and the limitations of their resources.

A case study provides richness and depth of qualitative findings, but presents difficulties in drawing generalisations from the particular<sup>1</sup>. Self help research in general is still building a set of methodological tools that are sensitive to the fragile self-determination of groups.

Researchers have indicated the need for small-scale evaluative research alongside self help groups: this study reflects this through active consultancy and partnership with the umbrella organisation to advance their agenda and clarify their long-term goals. Local support is enabling rather than prescriptive, carried out with a strong protective ethos and a respect for the independence of groups: so should work with the support agency themselves.

### 1.4. Methodologies

One approach is to view the use of the Internet as an attempt to further the knowledge of the organisation, to enhance its understanding or advance an agenda (however that is to be defined.) "Knowledge is a dynamic, self-modifying state. Knowledge changes in the course of

acquiring information,” leading to a “cyclical refinement of information needs.” Dialogue, interactivity and ongoing assessment are therefore important features of information exchange<sup>2</sup>. The organisation can be seen as an information user, and the Internet as both a system and a source. The channel itself has a value. The specific information needs of self help groups are difficult to discern, arising as they do in response to specific personal issues. But I have attempted to equip the organisation with structured, evaluative research tools which can be deployed across a range of subject-specific tasks, in addition to general tools which support their less tangible aims and mission.

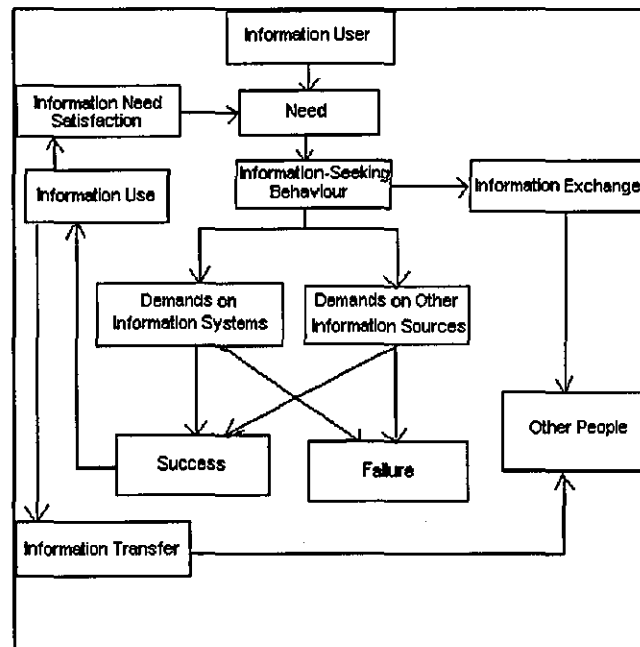


Figure 1.1 Wilson's Model of Information Seeking Behaviour

“All methods of research are ultimately substitutes for the fundamental method of observation<sup>3</sup>.” There are no pre-defined research solutions for such a complex and subjective series of processes<sup>4</sup>. The Objectivist paradigm is

ill-suited for providing a more authentic picture of...perceptions of...information environments and more integrated accounts of...information-seeking activity<sup>5</sup>.

In practice this is a non-linear operation and more creative, qualitative techniques are required to map the overlapping information management, communication and behavioural spheres. This is interaction within a social environment, not a simple user-system relation, and has emotional, intuitive, serendipitous and organic elements. What does this information *mean* to its users? Analysis of Internet sources alone is insufficient: an awareness of the *role* they might

perform, and the tasks that prompt information need, is vital<sup>6</sup>. This is part of a wider life cycle of information, covering objective-setting, source identification, acquisition or *creation* of information, its communication, use and retention<sup>7</sup>.

As a result, a "grounded theory" approach is adopted, centred on Self Help Nottingham as a participant in the research process. Informal semi-structured interviews were held at regular intervals to assess the team's needs, its knowledge base, organisational structure and function, and more general aims and ambitions.

In a practical sense, the WWW site design process involved regular meetings in Nottingham and e-mail dialogue, and included a two-hour presentation and discussion of the issues underpinning the project to all SHN core staff, outlining initial findings from the literature review and early Internet survey, giving background on the Internet, defining terms, and inviting ongoing input into the project. In practice, through limited time and resources, this has been channelled through the Information Officer. This follows a model of

research/review⇒develop working model⇒testing/feedback⇒re-assess and re-model

which extends not only to the overall project partnership, but Internet searching too. As content for the site filtered through, the model was reworked; as evaluation of sites increased an awareness of "best practice", features were incorporated into the working model, the two processes taking place in parallel as updates were sent to SHN and case studies reported. Timing, perception of the project aims, learning curves and motivation all influence the patterns of interaction.

In addition to the outline above and the related chapter on IT implementation in the voluntary sector (Chapter 7), the portfolio of methodologies used for this project also includes elements of content analysis and constant comparative analysis (in the support group case study), which will be dealt with in Chapter 4.

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<sup>1</sup> Grunow, Dieter. Why we need data: observations on evaluation research in health-related self help. In: Humble, Stephen. & Judith Unell, eds. *Self-help in health and social welfare: England and West Germany*. 1989, p. 86.

<sup>2</sup> Badenoch, D. et al. The value of information. In: M. Feeney & M. Grieves, eds. *The value and impact of information*. 1994, p. 14.

<sup>3</sup> Wilson, T.D. Object or participant: the information user in information research. *Swedish Library Research*, 1990, 3, 5-16.

<sup>4</sup> Barry, C.A. Critical issues in evaluating the impact of IT on information activity in academic research: developing a qualitative research solution. *Library and Information Science Research*, 1995, 17, 130.

<sup>5</sup> Ellis, D. Modelling the information-seeking patterns of academic researchers: a grounded theory approach. *Library Quarterly*, 1993, 63(4), 469.

<sup>6</sup> Leckie, G.J. et al. Modelling the information seeking of professionals: a general model derived from research on engineers, health care professionals, and lawyers. *Library Quarterly*, 1996, 66(2), 161-93.

<sup>7</sup> Wiggins, Bob. What do we really mean by information management? *Information Management and Technology*, 1994, 27(4), 162-8.



## Chapter 2: Defining Self-Help Activity

### 2.1. Introduction

The terminology surrounding self help requires a considerable amount of detailed examination if a common understanding is to be reached concerning its activities and protagonists, so that informed, effective, targeted decisions can be made in support of its groups and their individual members. The term "Self Help" has been used in a range of contexts, many of which bear little or no relation to what is understood by self help in the United Kingdom; as an umbrella term it also fails to include many of the synonymous activities denoted by variant terms in the consumer health information field, both in the UK and US: "support groups", "mutual aid groups" and "mutual aid/self help-groups."

As a concept, self help almost refutes definition. Many social scientists, on both sides of the Atlantic, have endeavoured to define it, to construct elegant typologies and set out its characteristics and distinctive functions.

What is attempted here is not a typology of typologies, nor an aggregation of those definitions set forward over several decades of social, anthropological, psychological and medical research into what may or may not be classed as a self help "movement". To try to distil the varied outpourings of these disciplinary approaches into a single working definition is folly: self help is a phenomenon that, by its very nature, sits awkwardly with that which seeks to be systematic, rigid, watertight and rational, since these properties relate too closely to those institutions and prevailing ideologies that self help defines itself *against*. The proliferation and diversity of self help groups is proof of their growing importance, but self help is a transient, fragile, fluctuating phenomenon with its own "internal momentum"<sup>1</sup> whose incidence is difficult to predict with any accuracy.

With the element of *self-determination* so critical to the distinctive function of self help activity, watertight definitions are apt to sink under the weight of imposed inclusivity. Typologies are useful to highlight variation, but miss the point that self help groups perform many functions at once<sup>2</sup>. As Self Help Nottingham's founder Judy Wilson has stated, "imposing definitions may cloud rather than clarify the concept"<sup>3</sup>.

## 2.2. An explanatory framework

Definitions are not designed...to constrain or straightjacket self help activities. Rather, they provide policy makers and funders with a shared baseline from which the effectiveness of self-help can be evaluated and resource decisions can be more efficiently targeted.

This requires a recognition of the common elements and range of self help activities.<sup>4</sup>

The following is not an account of self help as historical documentary tracing the theories of Samuel Smiles and Peter Kropotkin or older philosophical antecedents. Rather, this sifting and filtering of the main corpus of work on self help activity will try to elucidate the key features of this complex matrix of organisation, function, communication and purpose, since it is vital to establish who is to benefit from those aspects of the Internet being studied here, and in what ways those benefits are to be derived. Integral to the question "what are the potential benefits?" are those surrounding the *suitability* and *level* of services and information, the *practical framework* by which they are to be delivered, and *sensitivity* to the specific context of service delivery.

## 2.3. What Self Help is not...

It is perhaps useful initially to pursue a negative line, excluding those subjects that use the term self help but do not fall within the scope of this study. Hence the array of "self-help manuals" in the field of computer software and other technological developments must be weeded from the results of any literature search across social science, medical and scientific databases. So too is it important to distinguish between references to "self-help programs" in the medical and psychological fields which refer to computer (software) programs to facilitate or assist in compliance with professionally initiated treatment regimes (computer-assisted group problem-solving, Computer Assisted Instruction, medical education software etc.)

## 2.4. Literature review

Self help (or, interchangeably, "self-help": many US researchers use the hyphenated term) became the subject of serious qualitative and quantitative social research in the United States in the early 1970s, reaching something of a watershed with the oft-quoted definition by Katz & Bender in 1976:

[Self-help groups are] voluntary small group structures for mutual aid in the accomplishment of a specific purpose. Usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change...the initiators and members of such groups perceive their needs cannot be met by or through existing social institutions. Self-help groups emphasize face-to-face social interactions and the assumption of personal responsibility by members<sup>5</sup>.

I shall return to this definition shortly, tying together many of its key features and assumptions with the work of later researchers.

An American influence has continued to pervade the self help research landscape through studies that have moved beyond a strictly social science viewpoint to include clinical outcomes research and psychological/behavioural aspects e.g. recovery from addictions. The US healthcare system [or lack of it] has undoubtedly shaped the American way of self help: US-UK comparisons reveal a similarity in the structure of definitions, but only after sifting through the plethora of "self-growth" pseudo-science material and filtering for an american emphasis on formalised, twelve-step recovery programmes such as Alcoholics or Narcotics Anonymous. These cultural difference will be more fully explored in the Internet chapters, where such variation is thrown into sharp relief.

The UK interest in modern manifestations of self help arose later than its US counterpart, but by the mid-1980s the term had gain recognition through writers such as Wilson<sup>6 7 8</sup>, Vincent<sup>9 10</sup> and Richardson<sup>11 12 13</sup>. European comparisons began to be drawn<sup>14</sup>. Jurgen Matzat's definition is worth quoting as an example of this European perspective:

Self-help groups are voluntary, mostly loose associations of people whose activities are directed towards a common coping with illnesses, psychological or social problems, by which they - either themselves personally or as relatives - are affected. Their goal is a change in their personal life situation and often greater influence on their social and political environment. In regular groupwork they stress authenticity, equality, a common language, and mutual aid.<sup>15</sup>

This definition will be unpacked in greater detail below, but it is important to note the tripartite division into "physical illnesses, psychological and social problems" (one could further subdivide illness into physical illness and disability, and add addictions as a cross-cutting

category). Those affected can similarly be extended to include “carers” in addition to sufferers and relatives.

Richardson’s 1984 definition is simpler, but benefits from a straightforward use of language and a flexibility in keeping with Self Help’s ability or right to define itself:

Self-help groups are formed by people who feel they have a common personal problem, typically concerned with medical, social or behavioural conditions, and have joined together in order to do something about it.<sup>16</sup>

This last point is perhaps deliberately vague, Richardson extending the role of self help groups to include the exertion of pressure through lobbying in a wider, public context. As we shall see in Chapter 5, Richardson locates self help within the battlefield of consumer rights, defined, to an extent, by their relationship to public agencies and professionals. Self help is thus “a valuable addition” to professional services, supplementary and cumulative in nature<sup>17</sup>.

Such research is underlined by an understanding that self help, as a social phenomenon tracked and delineated by social scientists, registers its impact differently on those whose lives are enriched by their involvement in it. Gay quotes Jill Vincent:

there is little sign the members are aware of or adopt a consciously worked out self-help philosophy or ideology. They are of course aware of the practical benefits of membership, but few take their understanding further than this.<sup>18</sup>

Most pertinent to the UK research was the national restructuring of health and social services by successive Conservative regimes, with its associated flowering of institutional, ideological and political debate. Those features relating to statutory care provision that are relevant to the present-day position of self-help activity and its support (*the consumer health context*) will be covered in greater detail in Chapter 5.

## 2.5. Key principles

### 2.5.1. Mutuality

The term Self Help contains something of an internal contradiction from the outset in its apparent emphasis on the individual *self* when a key defining feature is that of mutuality, of shared *group* support. While individualism is an integral part of why members approach self help groups (to effect some change in their personal life situation, to alleviate or solve a problem, to discuss or obtain information) and indeed the benefits derived are in many respects individual, the prevailing emphasis is on the *collective* nature of self help activity, the interdependence of individuals in groups and the strengths of common purpose. Integral to this group formation is an assumption of equality<sup>19</sup>.

### 2.5.2. Shared Experience

This commonality or “shared reality<sup>20</sup>” is grounded in the understanding that the type of support offered by self help groups is based on lived experience, of having “been there”, of identifying with others and thereby obtaining a fuller insight into the totality of issues surrounding a particular life situation and its effects on one’s peers; in sharp contrast is the detachment of the clinical-professional experience and its resultant imbalances in power, knowledge and control. Authenticity and a sense of equality result from what Gaioni terms “this unique perspective<sup>21</sup>”.

Exploring this idea further, it is possible to define this commonality as a product of discrimination or “negative status<sup>22</sup>”, of needs not being adequately met or even recognised. Here the arguments become more political in tone, with Self Help as a response to “isolation, depersonalisation and breakdown of human values in industrial societies in general, and in technological medicine in particular<sup>23</sup>.” Activity is frequently “motivated to counteract the effects of marginalisation, stigmatisation, isolation and lack of recognition,<sup>24</sup>” in short: disempowerment. Within this functionalist framework of understanding, self help arises to meet unmet/unrecognised needs, or serves as an alternative route to existing services which are meeting needs inadequately.

### 2.5.3. Self-determination & Group ownership

Common attributes promote common interests. Self help groups are voluntary affiliations run by and for their members, where decision-making power and choice lies with those who share the experience/situation, a democratic principle which does not preclude professional involvement but which ensures that any such involvement is sanctioned by group members [ramifications of this will be explored in the discussion on open/closed electronic support groups] Such independence also means self help groups are non-profit, although those that are local branches or chapters of a larger national organisation will have variant reporting and support structures.

### 2.5.4. Active Participation & Serial Reciprocity

Self-help meetings (whether face-to-face or electronic) are based on the exchange of experiential knowledge. The helper-helped role is usually shared, with roles often informal and interchangeable<sup>25</sup> although some individuals may “become expert<sup>26</sup>” as a result of their particular experience or access to information, with consequences for group equality and empowerment. The participatory nature of group involvement combats isolation, viewing individuals as consumers of health or social care and not merely passive recipients. It is this “serial reciprocity”, the ability both to give and to receive over a period of time, that Richardson highlighted<sup>27</sup> as giving self-help its basis at the level of personal involvement and experience (distinct from the one-way patient-professional or recipient-volunteer models of service delivery.) The people who share the experience or situation are the direct or indirect beneficiaries of self help activity.

In modern parlance, self help group members are both consumers and service providers/policy makers within a framework they define and control, shaped by their experiences and emerging needs. Borman<sup>28</sup> rather convolutedly terms this a “proactive adaptive capacity”, based on experiential learning within a networked “knowledge base”, viewing the self-help group as an altruistic “quasi-extended family” that maintains its own value system and a “fixed community of beliefs” [c.f. narrative theory, Chapter 4], its grassroots leadership “articulating” group needs to professionals.

## **2.6. Types of self help activity**

Within the diversity and fluctuating dynamism of self-help activity, however problematic the task of defining it, certain types or categories of self-help group can be discerned. These categories are far from watertight, with many groups overlapping.

### **2.6.1. Issue specific groups**

Groups organised around a particular social or health-related issue are characterised by those aspects of commonality and shared experience detailed above. They provide emotional support and practical coping skills, exchange or provide information, campaign on behalf of members or a wider community, provide services or involve professionals in a facilitating or advisory role.

Such groups may be initiated by individuals (self-help as spontaneous convergence) or by health and social service professionals who observe an unmet need for support (self help as alternative service delivery). Groups may reach a plateau, based on factors as diverse as geographical area or rareness/specificity of condition, or continue to grow into more formally organised agencies or registered charities with regional or national structures<sup>29</sup>. Membership is more often than not fluid.

### **2.6.2. Community Development**

It is possible to view self help as a subset of wider community development, or a specific form of community development which contains many of its aims. Based around specific issues or target groups, such as ethnic minority voluntary action or rural action<sup>30</sup>, these groups work more closely with community development workers in an attempt to gain more influence within local power structures and impact on the community environment.

### **2.6.3. Psychotherapeutic Self Help**

Many of the terms discussed above (isolation, stigmatisation, emotional support) have a strong psychotherapeutic slant, as the later analysis of electronic compared to face-to-face self-help interactions will show. Many issue specific groups contain elements of psychotherapeutic groupwork: eating disorders, abuse, drug dependency, etc. As subsequent chapters will show,

this type of self help activity is strongly represented in the US conception of self help. Both traditions have to combat to some extent the perjorative stereotypes of tea and sympathy or the poor man's psychotherapy.

<sup>1</sup> Humble, Stephen. & Judith Unell, eds. *Self-help in health and social welfare: England and West Germany*, 1989, introduction, xi.

<sup>2</sup> Richardson, Ann & Meg Goodman. *Self-help and social care : mutual aid organisations in practice*, 1983, p. 141.

<sup>3</sup> Wilson, Judith M. *Supporting self help groups: an action research study based on the work of the Nottingham Self Help Groups Project between 1982 and 1983*. MPhil dissertation, Department of Social Sciences, Loughborough University of Technology, 1987, p.7.

<sup>4</sup> Hyatt, Jenny & Jude England. *Investing in the heart of change: the case for resourcing the support and development of self help activities*, 1995, p.5.

<sup>5</sup> Katz, A.H. & E.I. Bender. Self-help groups in western society. *Journal of Applied Behavioral Science*, 1976, 12 (3), 265.

<sup>6</sup> Wilson, Judy. From philosophy to partnership. In: Humble, Stephen. & Judith Unell, eds. *Self-help in health and social welfare: England and West Germany*, 1989, pp. 128-135.

<sup>7</sup> Wilson, Judy. Local support for self-help: more difficult than it looks. In: Humble, Stephen. & Judith Unell, eds. *Self-help in health and social welfare: England and West Germany*, 1989, pp. 136-146.

<sup>8</sup> Wilson, Judith M. ref. 3.

<sup>9</sup> Vincent, Jill. I don't believe in data...In: Humble, Stephen. & Judith Unell, eds. *Self-help in health and social welfare: England and West Germany*, 1989, pp. 62-73.

<sup>10</sup> Vincent, Jill. [Editorial]. *Mutual Aid and Self Help*, 1987, 3, 2-3.

<sup>11</sup> Richardson, Ann & Meg Goodman. Ref. 2.

<sup>12</sup> Richardson, Ann. English self-help: varied patterns and practices. In: Pancoast, D.L. et al., eds. *Rediscovering self-help: its role in social care*, 1983, pp. 203-221.

<sup>13</sup> Richardson, Ann. *Working with self help groups*, 1984.

<sup>14</sup> Humble, Stephen. & Judith Unell, eds. Ref. 1.

<sup>15</sup> Matzat, Jurgen. Away with experts? Self help groupwork in Germany. *Groupwork*, 1993, 6 (1), 30-42.

<sup>16</sup> Richardson, Ann. Ref. 13, p. 30.

<sup>17</sup> Richardson, Ann. Ref. 12, p. 210, 215.

<sup>18</sup> Gay, P. *Getting together: a study of self-help groups for drug users' families*, 1989, p. 58.

<sup>19</sup> Wann, Mai. *The development of "self help" activities [summary]*, 1995, p. 2.

<sup>20</sup> Thorman, Susan. *Journey through self help*, 1987.

<sup>21</sup> Gaioni, Kathleen. Rx:self-help. *The New Physician*, 1988, July/August, 31



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- <sup>22</sup> Kingree, J.B. & R. Barry Ruback. Understanding self-help groups. In: Powell, Thomas J., ed. *Understanding the self-help organization: frameworks and findings*, p. 273.
- <sup>23</sup> Gann, Robert. *The healthcare consumer guide*, 1991, p. 23
- <sup>24</sup> Hyatt, Jenny & Jude England. Ref. 4, p. 4.
- <sup>25</sup> Hasenfeld, Y. & B. Gidron. Self help groups and human service organizations: an interorganizational perspective. *Social Service Review*, 1993, June, 218.
- <sup>26</sup> Posner, Tina. The development of self-help organisations: dilemmas and ambiguities. In: Humble, Stephen. & Judith Unell, eds. *Self-help in health and social welfare: England and West Germany*, 1989, p. 54.
- <sup>27</sup> Richardson, Ann. Ref. 12, p. 207.
- <sup>28</sup> Borman, L.D. Self help/mutual aid groups in strategies for health. In: Katz, A.H et al., eds. *Self-help: concepts and applications*, 1992, pp. xxi-xxii.
- <sup>29</sup> Hyatt, Jenny & Jude England. Ref. 4, p. 1.
- <sup>30</sup> Hyatt, Jenny & Jude England. Ref. 4, p. 2.

## Chapter 3: Self Help Groups and Electronic Communication

### 3.1. Introduction

Reviewing a subject so characterised by its novelty, the diversity of its activity, and the cultural influences of its medium, presents difficulties in attempting to convey an accurate picture of the electronic self help phenomenon as it exists at any given time. Much of the current evidence relating to the benefits of electronic self help is predominantly anecdotally-derived, since much of the research connected with it has yet to reach beyond the small-scale, speculative or unsystematic.

### 3.2. Methodology

As indicated earlier, a fluid, self-reflective, often non-linear approach was dictated by the equally fluid terminology. As a variant term was uncovered, search strategies were revised. As prominent author/researcher names arose new leads were pursued. Above all, the Internet's underlying structure encourages the following of hypertext links from site to site, document to document; encountering revision, addition or unexplained deletion was a regular occurrence.

### 3.3. Sources

The multidisciplinary nature of Self Help presupposes a multidisciplinary approach to information sources, ensuring that clinical/medical, psychological, social science, information and computer science, and journalistic perspectives and research are thoroughly covered by a range of subject databases of traditional academic peer-reviewed literature. CD-ROMs included ASSIA Plus<sup>1</sup>, British Humanities Index<sup>2</sup>, LISA<sup>3</sup>, British Newspaper Index<sup>4</sup>, PsycLIT<sup>5</sup>, and INSPEC<sup>6</sup>. Online ISI databases accessed through BIDS included the Social Science Citation Index<sup>7</sup>, Science Citation Index<sup>8</sup>, IBSS<sup>9</sup> and Embase<sup>10</sup>. Internet search engines, resource guides, subject-specific gateways and databases included the US National Library of Medicine's PubMed<sup>11</sup> version of Medline (to facilitate use of MESH headings), Alta Vista's advanced search mode<sup>12</sup> (with Boolean operators) and Metacrawler<sup>13</sup>, BUBL<sup>14</sup>, OMNI<sup>15</sup>, NISS<sup>16</sup>, SOSIG<sup>17</sup>, and the Argus Clearinghouse<sup>18</sup>.

Search terms differed according to the indexing structures of the various databases consulted, but covered variations on a theme of *electronic/online/computer-mediated and self*.

*help/support groups* etc., with truncation and Boolean refinement where permitted. More general approaches were required for some smaller resource guides, requiring an inevitably cumbersome filtering of inappropriate "self help guides" and elaborate accounts of psycho-spiritual self growth and "personal wellness" (the US bias of the Internet becoming swiftly apparent.)

### 3.4. Internet Problematics

However, such an approach is not in itself sufficient to chart the overriding majority of electronic activity, discussion and debate that has yet to filter down to the traditional academic research level. As both a source of information and a community of users, the Internet is a curiously self-documenting medium. As an information resource "reflecting the spectrum of modern culture, society and human endeavour, the Internet is unparalleled<sup>19</sup>", but such reflection is prone to distortion and refraction. Lack of standardisation or consistency in its organisation make information retrieval a haphazard business: it is virtually "impossible for a single (meta)directory to cover its field comprehensively", nor is it "clear how comprehensive or authoritative a directory is, what it aims to include or how often it is updated<sup>20</sup>." Such difficulties affect both macro- and micro-interpretations of what the Internet has to offer an organisation, since uncertainties arise at both the level of individual documents or sites and at the level of overarching search engines, gateways, catalogues and directories (the very means of *accessing* those information resources).

Well rehearsed arguments over the difficulties of utilising the Internet centre on the fact that it is an inherently problematic and transient medium, an ethnographic community (of sorts) whose members leave traces of their explorations and wisdom in an unsystematic fashion. An extreme view of this freeform aggregation of resources might be termed "the cataloguer's nightmare", expressed in the opinion that the Internet is a "disorganised mess" with fragments "added daily by the myriad cranks, sages and persons with time on their hands who launch their unfiltered messages into cyberspace<sup>21</sup>."

As Pierson states in his assessment of the potential of the Internet for social workers,

No claim is too extravagant for those who either promote its possibilities or condemn its lawlessness...it promises much, delivers modestly, but rewards the patient user occasionally<sup>22</sup>,

such patience being tested by the demands placed on the user to filter and re-evaluate with alarming frequency, in addition to those problematics of peak usage times<sup>23</sup>, accuracy and validity of content, impermanence of hypertext links, and richness of access provided by the individual computer and/or its network (heavily dependent on technical aspects such as browser capability, connection speed, etc.)

Where the Internet is concerned, one chooses one's metaphor for its chaotic organisation from the storehouse of literary-cultural and artistic archetypes: mazes<sup>24</sup>, winding paths, chinese puzzles, Pandora's Boxes<sup>25</sup> and ransacked libraries. Such problematics of Internet use lie, at first sight, in its navigational uncertainties and the often idiosyncratic responses of its search tools. As will be explored later, such eccentricities are compounded by deeper issues of quality and authority, but at this stage it is sufficient to accept that the culture of Internet research requires a portfolio of research techniques that take that culture into account, and that a critically-informed approach utilising a range of search methods can nevertheless uncover valuable information sources.

In any case, such disorganisation or *dysfunction* is itself an appropriate phenomenon for study : the very problematic nature of locating Internet information feeds dialectically into an analysis of the *value* of the Internet as an information source, such problematics fuelling discussion on issues of quality, authority, utility, functionality and appropriateness to an organisation seeking to build an Internet strategy into its information and related services. Such issues will be explored in the evaluation of specific sites and the design of the web resource.

### 3.5. Accounts of Electronic Self Help Activity

#### 3.5.1. Issues of Evolution and Equivalence

The clearinghouse model outlined in Chapter 8 is underpinned by a belief that electronic linkages are inherently beneficial, in that they represent a natural extension of face-to-face self-help interaction carried on by other means: telephone, correspondence, or teleconferencing<sup>26 27</sup>. Such alternative networks are seen as natural antecedents to *Internetworking*, the latter fulfilling the promise of earlier, more rudimentary initiatives<sup>28</sup>. Madara has served as the leading exponent of this evolutionary approach that champions electronic communication as a vehicle of "high tech"/"high touch" community development<sup>29</sup>. The terminology used has undergone only slight alteration since the mid-1980s, in line with the realisation of many of the

futuristic predictions about “electronic linkages”, their social benefits and access for mass populations. To an extent, among certain sections of the US population at least, it might now be possible to argue that the networked home has indeed arrived, with all its potential for combating isolation, providing information and extending support. Problems with extending this model, however tentative it may be, beyond this US context will be developed later.

Whether electronic self help is equivalent to face-to-face self-help, in what ways it differs, and its applicability to the UK self help context, are questions central to this thesis. At present, little or no *evaluative* research has been carried out into the extent and effectiveness of electronic self help, much of the published material being characterised by a positive, laudatory approach that equates the *potential* for networking with its *actual* effects. It is rather like developing a logical argument along the lines of: self help is a process of bringing people together; electronic communication is also a process that brings people together; *ergo*, electronic communication must support self help. It is perhaps symptomatic of a “first wave” account of a social phenomenon that its sheer novelty or newsworthiness encourages an unquestioning engagement, particularly since self help in its “traditional” face-to-face form is only just beginning to register an impact on the clinical medical and psychological research scale in any systematic and evaluative way. What is required is a “second wave” evaluative approach to electronic self help, an approach that is critical, that opens up questions and recognises limitations rather than simply adding to the recent flurry of anecdotal journalistic accounts of Internet-as-social-benefactor.

### 3.5.2. Internet accounts

Ferguson's *Guided Tour of Self-Help Cyberspace*<sup>30</sup> represents a “first wave” approach within the framework of consumer health informatics and participatory medicine, reflecting his promotion of online health information in his printed work<sup>31</sup>. He too posits an evolutionary theory of traditional in-person self help functions (altruism, activism etc.) reconfiguring themselves online as forum hosts, list moderators, coordinators and webmasters. Interestingly, he stresses the need to move away from a conceptual model of the Internet as a universal medical encyclopedia, preferring instead to seek an ongoing conversation or involvement within an online community, a consumer interface with healthcare systems. Such resources can be distinguished as community-based or clinically-based, depending on the lay or professional status of the source. Ferguson may seem futuristic in his views on patient-clinician direct e-mail consultation and other Information Age Health Care advances, but fee-based online

psychiatric consultations, through organisations such as Shrink Link and Cybershrinks, are already with us<sup>32 33 34</sup> and are likely to keep pace with Internet growth as a whole. Ferguson's hierarchy

- individual self-care
- friends and family
- self-help/community networks

- health professionals as facilitators and coaches
- health professionals as partners
- health professionals as authorities

usefully demonstrates the conviction that the lay-professional continuum is being reshaped by online developments. The fact that clinical research is, potentially, available through Internet sources accessed in the home or public library, offers a radically redrawn map of patient awareness and involvement. Ferguson reveals the extent to which this view has been developed in American (while at the same time highlighting, by its very language, the cultural and organisational differences between US and UK conceptions of healthcare delivery) when he writes:

We will have arrived at true Information Age Health Care when we all take it for granted that the *primary* practitioner in our health care system is the informed, empowered online layperson, and that the main role for health professionals will be as coaches, teachers, supporters, and cheerleaders for system wide, computer-supported high-quality, low-cost self-managed care<sup>35</sup>.

A primary care-led NHS, with an enhanced role for General Practitioners as commissioners of healthcare (in one guise or another), is unlikely to meet such descriptions of healthcare "coaches" and "cheerleaders" with anything other than a furrowing of brows and shaking of heads.

Smyth's account of the Cleveland Free-Net's Alzheimer's Disease Support Centre<sup>36</sup> describes a range of information and support services available through bulletin boards, moderated e-mail question-and-answer sessions and open electronic forums. Such activity represents the type of consumer-professional partnership that many commentators put forward as a solution to rising health and welfare costs. Similarly, Kang's experience with disability-related self help bulletin boards in Hong Kong<sup>37 38</sup> describes grassroots activity, such as teleworking or remote tutoring projects, which have gone on to attract major corporate sponsorship, an example of

collaboration extending access to a community for whom the benefits of electronic "mobility" and an equalisation of status could not be more pointed.

The series of conferences *Partnerships for Networked Consumer Health Information*<sup>39 40</sup> sponsored by the National Health Information Center, the Office of Disease Prevention and Health Promotion, and the Department of Health and Human Services, give an indication of the breadth of consumer health informatics in the US. Those discussions most closely related to self help issues are inevitably shaped by the prevailing US concern with technology as agent of social change and the empowerment of the patient. A complex matrix is mapped out, involving consumers, professionals, systems developers, Internet service providers, and government funders. The slippage in terminology between self care and self help is never more apparent than during these discussions on active participation. It appears they amount to one and the same thing. Leading self help Internet figures Madara<sup>41</sup>, Ferguson<sup>42</sup> and Grohol are to the fore, chairing workshops whose transcripts go some way to proving the maxim that Britain and the US are two nations separated by a common language. Issues of accuracy of information are often swept aside or treated in a dangerously vague fashion ("it is relatively accurate and okay to point patients to it", "medical facts are not actually factual", "acquisition of information relieves suspense from not knowing" etc.<sup>43</sup>) and issues of access given scant coverage. Ferguson's hierarchy is implicit in many of the contributions which relegate health professionals to an *ad hoc* brokerage role as supporters and facilitators of healthcare, their status as experts stripped by a laity suddenly empowered through technology. Alan Douma comments

There is a plethora of opportunities for accessing help, and it is the duty of the healthcare professional to understand how this help is obtained and to be able to point to a resource.<sup>44</sup>

Is this clinical care as practiced by clinicians, or Internet information specialists? Does access to Medline bring the ability to self-diagnose? In promoting the improvements in access to information there is the risk that the professional/clinical baby is thrown out with the bathwater.

King's collection of resources relating to online support groups intersects with the wider study of the psychology of virtual communities, self help groups offering themselves (willingly or unwillingly) as rich case studies in computer-mediated interaction. King has covered general

aspects of cyberspace psychology<sup>45 46</sup> and specific issue groups: gender identity disorder<sup>47</sup>, addiction<sup>48</sup> and suicide<sup>49</sup>. He notes the therapeutic benefits many of these groups appear to give their members (58% of whom contact each other by traditional means<sup>50</sup>), viewing them as a valuable additional tool in a range of support group settings. Of similar standing is Phillips' informal study of the Adult Children of Alcoholics group, comparing its formats: Internet Relay Chat, e-mail discussion list and in-person groups<sup>51</sup>. Aspects of both King and Phillips' work will form part of the discussion of advantages and disadvantages below.

### 3.5.3. Journalistic accounts

The social welfare aspects of Internet use have not gone unnoticed by the UK broadsheets, many of which publish specific IT supplements. Specific conditions, such as Chrohn's disease<sup>52</sup> and Down's syndrome<sup>53</sup> are treated anecdotally, as is a voice-activated system run by a paralysed Salvation Army officer<sup>54</sup>. General aspects of the online support phenomenon are also treated<sup>55</sup>, along with virtual psychiatry<sup>56</sup>. This latter discipline is the most common focus for generalist accounts, since it encapsulates those implicitly psychological aspects of human-computer interaction: witness the visual portrayal of the computer-as-psychiatrist in Spinney's review<sup>57</sup>. She details the use of e-mail by the Samaritans as an extension of their telephone services, making the salient point that the demographic profile of one of the population groups most vulnerable to depression is men aged 18-24, making them a target group for electronic counselling services due to their high computer use<sup>58</sup>. Spinney's account is balanced by comments from those psychotherapists who feel e-mail cannot provide the extra verbal and non-verbal information (tone of voice, body language) required to support a relationship based on "subtleties of human judgement."<sup>59</sup> Issues of protection and licensing are also raised, underlining the sensitivity and vulnerability of those who might benefit most from online therapy. Without registration or regulation, how can users be certain of the credentials of those providing counselling? This reflects the wider concern with the authenticity of health information on the Internet discussed in Chapter 12.

"The chief medium through which group therapy is being conducted on the Internet is that of newsgroups<sup>60</sup>", in particular those with the *alt.support* prefix. Zgodzinski outlines the contributions of those counsellors, advice columnists and therapists who are using the Internet as an extension of their existing service patterns, and restates the argument that online support equates with its face-to-face form, "the honesty of the postings and sincerity of the replies



[making] it evident that the newsgroups are serving an important function in the lives of the sufferers who gather there.”

Other American journalistic accounts offer similar anecdotal overviews<sup>61 62</sup>; Lempert focuses on Scolamiero's support group on brain tumours<sup>63</sup>; others cover parenting<sup>64</sup>, patient-clinician relationships<sup>65</sup>, menopause<sup>66</sup>, the elderly<sup>67</sup> and self-managed care<sup>68</sup>.

#### 3.5.4. Academic-related accounts

Finn has conducted research into specific on-line groups in the areas of sexual abuse<sup>69</sup> and addiction recovery<sup>70</sup>, work which may at some later date be perceived as seminal, not least for his glaring ethical error in leaving the name of the newsgroup, dates and times of messages etc. unaltered in his published results. (The social sensitivity of such research will be fully developed in Chapter 4.) Finn indicates rapid growth in what he rather convolutedly terms Computer-based Self-Help/Mutual Aid (CSHMA) groups, viewing them as part of a wider set of “special interest groups” on commercial hosts (such as Compuserv, Genie, Prodigy and America Online) and privately-owned BBSs (Bulletin Board Systems) such as FidoNet and its associated “echo conferences”<sup>71</sup>. Taking the Recovery BBS as an example, Finn downloads statistics on number of callers, their demographic profiles (age/sex), frequency of calls, drop out rates etc<sup>72</sup>.

A frustrating aspect of this research is that it is content simply to restate its unsystematic and generalised review in each article Finn published from 1994-1996, highlighting the lack of research, encouraging more systematic attempts but not actually performing any himself. Overviews and introductions need swiftly to catch up with developments on the ground.

Weinberg et al. have conducted a small-scale research project into the therapeutic effects of a computer-mediated support group for 6 breast cancer patients<sup>73 74 75</sup>. Their work centres on the potential benefits of such support in overcoming *logistic* and *stylistic* barriers which would otherwise prevent attendance. After an initial period of IT familiarisation, participants used menu-driven software on loaned home computers linked to a bulletin board to discuss the impact of their medical condition on their lives at the personal, social, familial and vocational level. After three months a survey was conducted to investigate the presence of Yalom's 10 factors of group therapy<sup>76</sup>.

- instillation of hope
- imparting information
- altruism
- socialising techniques
- group cohesion
- catharsis
- imitative behaviour
- universality
- interpersonal learning
- corrective recapitulation of primary family group

All ten were considered present by participants, with group cohesion (the forming of emotional bonds characterised by openness and acceptance), universality (to combat isolation) and the instillation of hope most prevalent. There was a moderate (but statistically non-significant) correlation between these therapeutic factors and the overall perception of the group's usefulness<sup>77</sup>. However, it is important to note the very small sample size and the specific condition of the participants, factors that severely limit the ability to generalise. Such research inevitably runs into the methodological difficulties associated with self-help groups [c.f. Chapter 4]

Alemi et al. conducted research into the benefits of a voice bulletin board for 53 pregnant women with drug addictions, comparing the impact of such a bulletin board with a control group of face-to-face support on such measurable outcomes as group solidarity, expression of emotional support, health status and uptake of medical services<sup>78 79</sup>. As such, the model is less relevant to informal self-help groups, since professional medical involvement was pronounced, discussions were formally initiated by a counsellor etc., and of reduced relevance to an analysis of electronic self-help since the primary mode of exchange was not textual but *verbal*. Given that the Internet is only beginning to develop verbal and visual aspects of communication at its leading edge, such findings as Alemi et al. make remain beyond the scope of current and near future technology for the overwhelming majority of potential participants. As such, the research represents a curious one-step-forwards, two-steps-back approach, discussing the potential developments of electronic support while implementing what amounts to a sophisticated, asynchronous telephone conferencing system.

Winzelberg's analysis of electronic support groups for individuals with eating disorders<sup>80</sup> is based on a discourse analysis of the messages sent by group members in an attempt to uncover aspects of group function and efficacy. The three most prevalent message categories or types were found to be "self-disclosure" (31%), requests for information (23%), and the "direct provision of emotional support" (16%). Of particular note is the finding relating to the time

group members participated: the peak usage was in the evening and late night, times when traditional sources of support and information are of limited availability (if at all.) Winzelberg concurs with Finn and others in the belief that "members of the electronic support group used the same assistance strategies as do face-to-face support group members<sup>81</sup>", emphasizing their potential as innovative and *low-cost* self-help services for future healthcare provision. Mayer's quality of life research focuses on breast cancer discussion groups, concluding that "the Internet has arrived as a force in our lives<sup>82</sup>", a medium to be exploited in partnership by professionals and patients.

Traditional clinical medical and nursing research have also noted the development of online patient meetings<sup>83 84 85 86 87</sup>, framing them within the context of consumer health information and reinforcing the view of them as a low-cost alternative social support mechanism. The range of conditions covered by Medline-sourced research include amyotrophic lateral sclerosis<sup>88</sup>, cancer<sup>89</sup>, disability<sup>90</sup>, genetic disorders<sup>91</sup> and body-image<sup>92</sup>. The value of Internet access to Medline to enable self-help support agencies and individual groups to access clinical literature on specific conditions or to gather resources on self-help's effectiveness will be discussed in Chapter 11.

Lamberg's account of a support group for sufferers of the rare skin *cancer cutaneous T-cell lymphoma (CTCL)*<sup>93</sup> represents a growing trend of reporting, albeit it anecdotally, the benefits of online patient support networks within peer-reviewed clinical research publications. Addressing the professional medical audience combines praise for the groups' work, highlighting its distinct personal contribution and rapid growth,

The frequent exchanges commonly foster intimacy and trust, creating a supportive virtual extended family...In March 1996, its first month, 6 people signed on. One year later, the group had 135 members in 15 countries...

while also recognising that professionals are often under attack from participants. Such advocacy encompasses a consumer health partnership approach, stressing the need for positive, non-threatening involvement by healthcare professionals. The Internet has simply made the process of lay referral more visible to those whose expert role is founded on exclusivity of access to forms of knowledge<sup>94</sup>.

The ease of swapping information on daily management of an illness is another benefit of

participation. [However] dubious assertions seldom go unchallenged. List owner Jones says she tries to let everyone speak out and to correct statements she knows to be wrong. She tells group members, "The best thing to do is to find a doctor who is currently treating CTCL-MF patients, usually at a large teaching hospital, and ask questions."<sup>95</sup>

### 3.6. Discussion and Analysis

In addition to recognising the actual and potential growth of electronic self-help groups and the mechanisms by which they can be developed, this research can usefully be distilled into a number of headings which serve to group together a range of advantages and disadvantages touched upon in other accounts. Underlining Finn's analysis is the assumption that, theoretically at least, the benefits and interactions provided by this computer-based version of self-help are the same as those derived from traditional face-to-face groups:

Members can share personal experiences, ask for and provide information and advice, show support and validation, take on the role of helper, and provide social interaction, despite the lack of in-person contact between members<sup>96</sup>.

Such advantages are therefore seen as being *in addition to* those provided by the traditional self-help model. As later discussion will show, this equivalence of electronic and face-to-face self-help interactions is far from certain.

### 3.7. Advantages

#### 3.7.1. Wider access to meetings

Access to self-help within the confines of the physical world is often a matter of geographical location, time and mobility. The virtual, electronic meeting-place ("cyberspace") does away with these logistical barriers, offering access to geographically dispersed populations (rural communities are often cited as beneficiaries in anecdotal accounts) and those who would not normally attend meetings due to lack of transportation, physical mobility<sup>97</sup> or full-time caring commitments. The "24-hour access" argument is also put forward, such networks offering catharsis (if not actual *support*) at inconvenient times.

It should be stressed that this advantage of convenience or flexibility of participation is dependent on *access* to the electronic self-help group through a computer located in the home. What is striking is the lack of attention given to questions of access in the US literature, such silence underlining the *assumption* of access to the required technology and skills. Herein lies a marked cultural distinction between US accounts of electronic self-help and the potential for extending the model to the UK context: in the US, home access is far higher, whereas the UK model may eventually be based on more public access points (public libraries, self-help support and other voluntary agencies etc.) One might also note the premium placed on convenience in American culture in general, and question whether convenience itself has become the goal, rather than being simply one aspect of achieving a more profound change in the way individuals can support each other.

### 3.7.2. Diffusing Dependency

These aspects of convenience, ease of scheduling and flexibility can potentially reduce the risk of over-dependence on individual group members, a process of sharing the burden among a wider group of participants. This flexibility does not preclude the need for intense support at key stages (e.g recovery from addiction) when electronic communication will not suffice, suggesting that such a form of self-help may have a place as a *supplement* to traditional delivery systems rather than a freestanding replacement.

### 3.7.3. Reducing the Isolation of Rarity

The international nature of cyberspace combats the problems of those who suffer from a rare or esoteric disorder or condition, such rarity causing isolation in a more restricted geographical self-help constituency. An infinitely wider community base brings a depth of perspective and sources of expertise unavailable locally. Self Help Nottingham's rare syndrome groups are concrete examples of how such fragile memberships could be extended.

### 3.7.4. Reducing barriers based on social status cues

Although held to be a defining aspect of self-help, as outlined in Chapter 2, in practice the equality between self-help group members may not represent equality of access or membership in a wider social perspective. Specific kinds of self-help groups may be dominated by particular social characteristics, such exclusion operating along class, gender or ethnic lines.

Addiction-related groups such as Narcotics or Alcoholics Anonymous have been depicted as white, middle-class forums<sup>98</sup>. As the NCVO Self Help Centre reported, “self-help activities can be exclusive and discriminatory...[there may be] difficulties in introducing equal opportunities practices into local groups<sup>99</sup>.”

The relative anonymity of electronic versions of self-help can potentially overcome such social status barriers or cues, since judgement is made on *content* alone. According to this argument, removal of the psychological hindrances of social class, age, gender, race, physical appearance etc. results in increased access and greater openness. In the virtual society, then, all messages have an equal chance of being read/heard, or at least the risk of them being dismissed on the grounds of appearance is reduced (since all electronic messages physically look the same as bodies of text, there are no cues as to the author's status). Wellman counters this view, believing the Internet is not a separate reality: “people bring to their on-line interactions such baggage as their gender, stage in the life-cycle, cultural milieu, socioeconomic status, and off-line connections with others.<sup>100</sup>”

### 3.7.5. The Realities of Access

Again, such arguments of enhanced access are based on the assumption that underrepresented or excluded groups have access to the technology that allows such “equality” to flourish, if indeed it does. Such a reduction of social status barriers will remain merely hypothetical as long as those groups remain on the wrong side of the technological divide in terms of “information rich” and “information poor”.

These issues of resourcing and demographic profiles are voiced by Littlefield, quoting the American IT educationalist Carvin:

The Internet parent culture is strong, but it is limited, and it will remain limited until Internet access expands into the homes of rural, poor and inner-city parents<sup>101</sup>.

Bound up with this fundamental point about equality of access is that of the profile of self-helpers compared to the profile of Internet users. If self-help is a predominantly female activity, how does this sit with the profile of Internet use dominated by financially stable, urban, degree-educated white males?

### 3.7.6. Internet demographics

Estimates of the size and character of the Internet show pronounced variation and should be viewed with a healthy degree of cynicism. Many of these surveys are based on a sample size of 1000, and give scant attention to social background. The income categories are so broad as to be unenlightening at the lower end of the social scale (besides, these are voluntary responses and income may be overestimated.)

Nevertheless, certain trends have begun to emerge: of the estimated 9.5 million American users, 7 million have access from the home<sup>102</sup>. Between 60-65% are men<sup>103 104</sup>, around 80% are white<sup>105</sup>, with an estimated average income across all users of \$63,000. Only 10% are from rural communities<sup>106</sup>. The dominant age range on the Internet is 18 to 35 years old<sup>107</sup>. In the UK, Roughly 35% of Internet users earn over £25,000 per year<sup>108</sup>. In terms of services used,

men are much more likely than women to use the WWW and such specialized applications as FTP and the Usenet. However, women are slightly more likely than men to use Internet email and to participate in Internet mail lists, underscoring a strong predisposition among women toward Internet communications features.<sup>109</sup>

What emerges is a distorted picture, but one which highlights the overriding issues of *access* and *representation*. Those most likely to benefit from self help are precisely those *least* likely to gain access to Internet resources, from the home or at work. This strengthens significantly the argument for counterbalancing measures: access initiatives through public libraries, schools and community development organisations. It is not within the scope of this dissertation to explore this field of "online communities" but the Web Resource designed for Self Help Nottingham provides links to UK community information sites and materials.

If new information technologies "distribute and disperse information capabilities" and "decentralise control of information and its concomitant power,"<sup>110</sup> then these wider issues of disenfranchisement become crucial. Technical advance is never without its social consequences. Rheingold, a pioneer of early virtual communities, wrote

We need to look closely at new technologies and ask how they can help build stronger, more humane communities - and ask how they might be obstacles to that goal. The late 1990s may eventually be seen in retrospect as a narrow window of historical opportunity...

to regain control over communications technologies. Armed with knowledge, guided by a clear, *human-centred* vision, governed by a commitment to civil discourse...<sup>111</sup>

and so asserts the need to place people at the centre of technological developments. What is occurring here is nothing short of the "informatisation of human life"<sup>112</sup>. The benefits of such human-centred progress are distinctly personal and social in character:

The technology that makes virtual communities possible has the potential to bring enormous leverage to ordinary citizens at relatively little cost - intellectual leverage, social leverage, commercial leverage, and most importantly, political leverage...but the technology will not in itself fulfil that potential: [it requires] an informed population<sup>113</sup>.

How is that informing process to take effect? What mediating structures are required to extend access to disenfranchised groups? What counterbalances need to be in place to ensure those most likely to benefit from self help are better represented among those utilising an increasingly important self help medium? If access is not equal, do partnerships with professionals who *do* have access become more vital? This is an extension of the argument that professional involvement, far from distorting or co-opting, provides a route into self-help activity<sup>114 115</sup> in order to counteract inequalities of access. Here is a medium (the Internet) being heralded by many as a natural extension of the village hall or church meeting room, yet so few accounts tackle the practical issues of access to the very means of participation or are content gloss over it with futuristic glimpses of what technology might be in the home in the next century. This fourth wave of Internet growth is commercial in emphasis, dependent on telecommunications networks and service providers. Framed as yet another form of social exclusion, Charlesworth and Cullen emphasise a facilitating strategy based on the European Union's notion of "accompaniment"<sup>116</sup> (access to information and support of more knowledgeable or experienced agencies) to counteract the view that

while this large scale transfer to digital technologies has the potential to increase massively access to information and services which were previously too expensive to distribute widely or too geographically remote, there remains the pressing concern that this "information revolution" may...bypass some sectors of society.<sup>117</sup>

Technological developments do not equate with widespread social benefits, both being shaped by wider social forces.<sup>118</sup>



### 3.7.7. Encouraging Participation and Promoting Communication

Related to anonymity and social status invisibility is the ability of reluctant members to test the waters of self-help without the same type of fears that might be present in a physical setting. (in fact, the six subject of Weinberg et al's case study were selected on the basis that they were unwilling to use face-to-face self-help groups<sup>119</sup>.) Such "lurking" is a process by which potential members can assess the norms, ideology and cultural signposts of group membership in advance of fuller involvement or commitment<sup>120</sup>.

Anecdotal evidence highlights a therapeutic benefit of electronic communication in comparison to face-to-face communication, namely an ability to reflect and to rationalise experiences through writing them down<sup>121</sup>. The asynchronous process of message delivery and response forces individuals to focus on their problem and increases openness (again related to anonymity) without the risk of this directness being distorted or diluted by other factors present in face-to-face groups. Finn argues that those with "interpersonal difficulties" in particular will benefit from such a physically distanced approach, with its ability to revise messages before sending them and the absence of nonverbal cues<sup>122</sup>.

It is also reported that online participation may evolve into face-to-face participation, with the electronic self-help group serving as a bridging mechanism<sup>123</sup>. Such electronic support may prove supplementary and concurrent, an important adjunct to face-to-face self-help groups.

### 3.7.8. Training for Professionals and Group Leaders

Exposure to a wider constituency of group members, with an increased range of experiences and situations, can assist professionals as facilitators working with electronic and face-to-face groups as well as group leaders themselves<sup>124</sup>. This is related to the process of "becoming expert" and the serial reciprocity inherent in the self-help dynamics of exchanging experiential information: contact with a wider range of experience feeds back into the group's life cycle, building a knowledge base that is richer than that which might be experienced only through physical meetings. Meetings can be logged and reviewed and advice on counselling techniques shared among group members collectively or individually between group leaders.

In cyberspace, restrictions on group size need not exist. Benefits of this form of communication derive from a critical mass of other users. This in itself presents questions concerning the

optimal size of groups and the risks of information overload when the floodgates are opened. In an article on a parenting newsgroup, Littlefield writes:

Not all the results of growth are positive. "There are way too many posts to keep track of now, which forces groups to split into less useful groups...Many people can't get the subgroups, or don't have time to read them all, and the sense of community is diminished."<sup>25</sup>

This may be a particular feature of unmoderated USENET newsgroups, since moderated groups and listservs/discussion lists can more effectively monitored or channelled by the list owner. List membership need not be automatic, so a ceiling on group numbers could potentially be imposed. To what extent this represents an undue degree of control depends on how a group conceives of or defines itself. A balance must clearly be struck between openness and universality, and a realistic appreciation of the personal dynamics of self-help. At what point can a sense of community be said to exist, and at what point does it begin to fragment? Is this something that can be given a numerical value at all?

### **3.8. Disadvantages**

In addition to those counter-arguments arising from the discussion above, other areas of concern include:

#### **3.8.1. Destructive interactions**

The very anonymity, and its resultant openness, which is put forward as a key benefit of electronic self-help may reduce social control to the extent that hostility or abuse occurs. There is little evidence cited that such occurrences (referred to in Internet terminology, or netiquette, as "flaming" but potentially more damaging than mere rebuttal) are anything other than rare, and therefore capable of corrective action by the group or list moderator. List "spamming" by advertisers (whereby mailboxes are deluged by irrelevant material) or other disruptions are a feature of many groups' online existence, something to be worked round. However, the sensitivity of such groups should preclude any complacency, as the case study clearly demonstrates.

### 3.8.2. Leadership issues

A lack of clear and accountable leadership may result if group membership becomes so extensive, and moderators or bulletin board operators are unregulated. However, this is not a disadvantage peculiar to online self-help, but rather is characteristic of self-help's participative democracy: leadership roles may be as fluid as the overall group membership, a combination of factors (time, commitment, expertise, strength of connection with the shared situation etc.) resulting in the relative informality and lack of hierarchy that gives self-help its distinct approach.

### 3.8.3. Promoting social isolation

Overdependence on computer-mediated communication reduces the bridging or supplementary role that online interaction can play and instead makes it a *substitute* for other forms of human contact. Indeed, the first cases of Internet addiction are reaching the clinical literature<sup>126</sup>. Such concerns form the faultlines of the virtual/actual communication debate. Can online versions of human interaction be held to be in some way equivalent to actual encounters? On one side of the divide it is believed that

Technology can indeed act as a prosthetic extension of human powers and communities. But virtual technologies are pernicious when their simulacra of relationships are deployed society-wide as substitutes for face-to-face interactions which are inherently richer than mediated interactions<sup>127</sup>.

### 3.8.4. Identity and Communication

Are such pseudo-communities constituted not by the sum of their individual parts, but composed of an aggregation of *personae*, of the virtual version of themselves that individuals choose to present? When community membership is as simple as subscribing to a discussion group, is the nature of the interaction different because one may disengage with little or no consequence?

It may be bewildering for us to create and learn the norms of online worlds, for to learn them is a complex process. It may bring people together, insofar as such learning is often collaborative, but it is equally as often frustrating and offputting.<sup>128</sup>

Citing Reid's analysis of Internet Relay Chat, MacKinnon emphasises the textual basis of online interactions:

Words, as we use them in speech, fail to express what they really mean once they are deprived of the subtleties of speech and the nonverbal cues we assume will accompany it<sup>129</sup>.

This returns us to the questions of access, since *literacy* is now central to membership of electronic self-help groups in a way it is not in face-to-face encounters. Are the symbols used to convey emotions substantial enough? Questions remain over the limited nature of online relationships.

What of recognition in the new, much-heralded communities carved out of cyberspace, where e-mail's rationalization of communication is already supplanting face-to-face interaction and the normative features that arise therefrom?...what if what gets recognised by the other is my *constructed* reality, which lacks the vulnerability of my primary identity, then what is thereby recognised by the other [is merely] my ideal construction of myself.... Such representations would be met by attitudes ranging from a suspension of belief to outright cynicism. Social interaction in such a space might well lose its validating dimension.<sup>130</sup>

Can community be created from *anonymity*? When Phillips highlights the throw-away nature of personae ("If one says the wrong thing and [is] rejected from the group [one] can create another identity and try again<sup>131</sup>") is this something to be striven towards? It smacks of an abrogation of personal responsibility, echoing Slouka's belief that such virtual communities are founded on escapism.<sup>132</sup> How far removed is this from Umberto Eco's notion of the "real fake", where the copy becomes the focus (in this case a "community") and the original disintegrates?

And yet, such virtual communities are growing apace. Illusory in their lack of physical presence, their effects would nevertheless appear to be very real to their participants. The case study that follows offers an insight into the type of interactions in an issue-specific group.

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<sup>2</sup> British Humanities Index [CD-ROM] (1985-1997) (Version 3.0.) Bowker-Saur, 1997

<sup>3</sup> Library & Information Science Abstracts [CD-ROM] (1967-1997) (Version 4.0) Bowker-Saur, 1997.

<sup>4</sup> British Newspaper Index [CD-ROM] (1990-1997) (Version 3.0) Research Publications, 1997.

<sup>5</sup> PsychLit [CD-ROM] (1974-1997) (Version 3.30) American Psychological Association, 1997.

- <sup>6</sup> *INSPEC* [CD-ROM] (1989-1997) (Version 4.40) Institute of Electrical Engineers, 1997.
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## Chapter 4: Online Self Help Group Case Study

### 4.1. Methodology: Narrative Theory as Conceptual Framework

Narrative theory provides a conceptual framework for understanding the nature and function of a community, based on a reality (or “community narrative”) constructed from the personal stories of its members. Schools, families, corporations and religious orders are founded on collective narratives. Stories order our experience, giving coherence and meaning to events and providing a sense of history and possible futures<sup>1</sup>. Such frameworks are pertinent to the study of self help groups for a number of reasons. As we have seen, a key characteristic of self help is the sharing of experiential knowledge among peers, a process of serial reciprocity, of giving to the group and receiving support or information in return. This can be seen as a cognitive process, intimately bound up with the development of identity and the transformation of a given situation. Individuals incorporate into their own life stories aspects of the community narrative (“community joining acts<sup>2</sup>”), a normative process by which the external and internal world feed into each other, so that dealing with a situation (discrimination, specific medical condition, negative status etc.) becomes a vehicle for self-transformation. Without the group as participatory audience, such a process could not occur: “stories told only to oneself do not benefit from the modification and coherence required for a listener<sup>3</sup>” This supports the claims that electronic self help produces similar benefits of ordering one’s narrative by setting down experiences on the screen.

Self help groups contain a duality of idiosyncratic, specific, personal accounts and shared, common experiences. Sharing is an interpersonal discourse that effects a fusion of the two, enabling members to clarify their personal problems while at the same time adding to the template or model of the group’s own guidelines for dealing with similar situations. It is because experiential knowledge is the product of the group that it has value, validity and authority for group members<sup>4</sup>, and is not imposed from outside.

### 4.2. Content Analysis

Although predominantly employed in the analysis of journalistic media and advertising<sup>5</sup>, content analysis is becoming recognised as a useful tool in information and library research<sup>6</sup>. Its premise is that content is influential, containing values and motives which it seeks to unearth by describing the attributes of messages, without reference to the intentions of the sender (the

encoding process) nor the effect of the message on those it is sent to<sup>7</sup>. It endeavours to be objective, explicitly formulating rules and procedures for categories of meaning and coding; systematic, consistently excluding or including material; and capable of generalisation, by linking the process to another factor.

Coding seeks to describe frequency (recurring patterns in content), the amount of a particular quality, the presence or absence of a quality, the origin or source and degree of intensity. The process of interpretation is a dialectical one, categories being reshaped as new content areas rise to the surface and significance reevaluated. As such, content analysis utilises a methodology similar to the constant comparative method of user studies, comparing "incidents" applicable to each category, developing core categories, then integrating categories and their properties so that the interpretation is shaped by the data. *Exempla* are used to serve as the concrete embodiment of categories and their properties<sup>8</sup>.

#### 4.3. Limitations

To what extent can a content analysis of electronic self help groups be conducted with validity, given that, for this research project at least, the study is non-participatory and so cannot be validated by members of the group itself? It is vital to recognise the limitations of what can realistically be attempted here, given the timeframe for research (extensive content analysis of groups would form a research project of its own), and the sensitivity of those studied.

Traditionally, self-help groups have posed methodological difficulties to researchers. External validity is impaired since random assignation and direct observation are difficult and ethically suspect. Groups are naturally occurring and their "intrinsic processes are automatically altered if interventions are implemented, since their members are both the tools for and the object of change<sup>9</sup>," the target and the agent. Manipulating these processes changes just those functions one wishes to examine.

As a social scientist, these groups present a self-documenting community, archiving their interactions over several months or years. Having subscribed to a list, one sifts through their collective correspondence without having to introduce oneself or gain their respect or trust. In the case of USENET groups, one utilises DejaNews<sup>10</sup> and wades through the archives. This opportunity to examine at close quarters electronic activity should be treated with respect<sup>11</sup>. King has highlighted these ethical aspects, citing the lack of informed consent, the potential for psychological harm. It is vital to ensure there are no permanent records that would allow

identification of individuals, to use non-reactive research methods, to maintain confidentiality and to protect the perception of privacy for the group as a whole<sup>12</sup>. This is contentious ground: is the Internet a public domain or private forum? Might USENET groups be accorded a different degree of privacy, by virtue of their "open access" status, than subscription-only or closed discussion lists? The present confusion should lead researchers to err on the side of caution where self help groups are concerned, removing any author identity references, time of posting information etc, and minimising the sort of word-for-word quotation that might identify the poster.

This case study is necessarily limited, but has been undertaken to provide an insight into the types of interaction and the nature of information exchange between members in an attempt to see whether the traditional model of face-to-face self help is transferred to the electronic medium intact. In the final analysis, if members feel the group is meeting their needs, whether it fits a model or not, then criticism is academic. But even a limited analysis of a single group's postings over a four month period serves as a microcosm for an assessment of those wider issues outlined in the previous chapter.

#### 4.4. Case Study - List Demographics

The list has existed for three years, but has changed hosts during that time.

Total number of users subscribed to the list:	259	Total number of users in United Kingdom:	8
Total number of users in United States:	199	Total number of countries represented:	15

[Note that these figures are approximate due to the fact that Internet Service Providers available internationally (such as AOL) are counted as "United States", even though the user may be resident in another country. Nevertheless, a strong US bias exists.]

It is difficult to assess how a list size of 259 compares with other condition-specific lists on the same server. A cystic fibrosis list has over five hundred, but anxiety disorders only 91 (by way of comparison, Bonsai owners have close to 400, and devotees of museums over 1,500.) Postings are archived in monthly logs, which are available *en bloc* by e-mail or can be searched through a Web interface by list members (access by password). An array of sort and browse functions (by author, date, topic) allows a particular thread to be followed, although this is dependent on the subject line remaining unaltered (only those messages sent "Re: " are included as direct threads. Any change of subject line will start a new thread, if not strictly a new topic)

4.5. Frequency of Postings

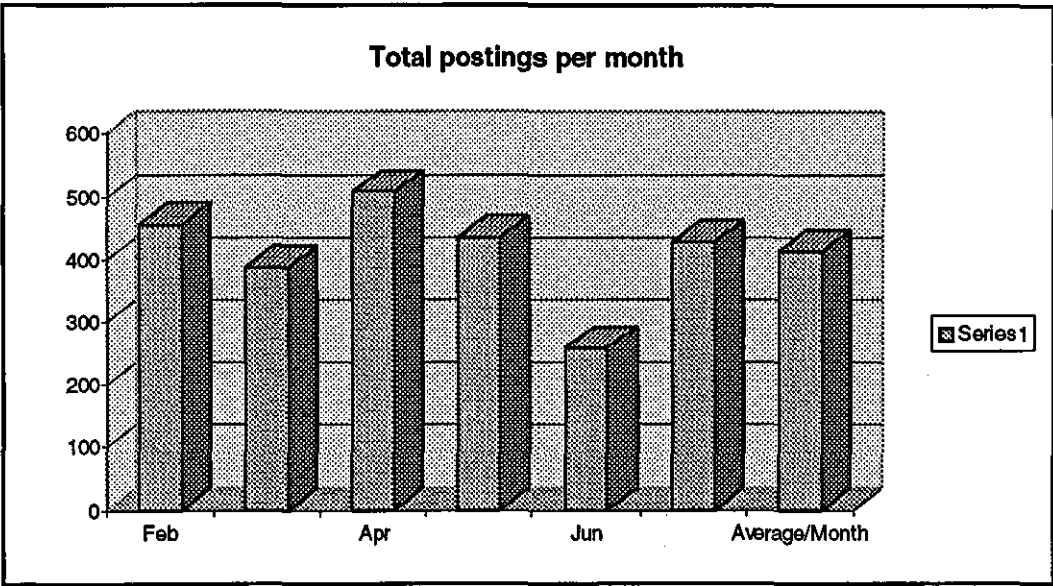


Figure 4.1. Total postings to group per month

It is possible to view frequency of postings and their origins as the electronic equivalent of measuring attendance at in-person meetings or the number of submissions within a meeting.

In July, taking into account multiple addresses, over 100 members sent messages (39% of total subscribers), with 11 individuals sending over 10 posts, accounting for 207 messages alone (48.5% of total messages). In June, 6 individuals sent over 10 messages (33.3% of total messages), compared to 15 individuals in both May (55% of total posts) and April (62.4% of total posts.) Comparison across the four months reveals that a core grouping of 12 members were represented in the >10 Posts/Month subset in at least three of the four months.

	Users >10 Posts	Posts by >10 Group	Total Posts	% of Total Posts
Apr	15	317	508	62.4
May	15	240	436	55
Jun	6	76	258	29.4
Jul	11	207	427	48.5

Table 4.1. Frequent Posters to Group

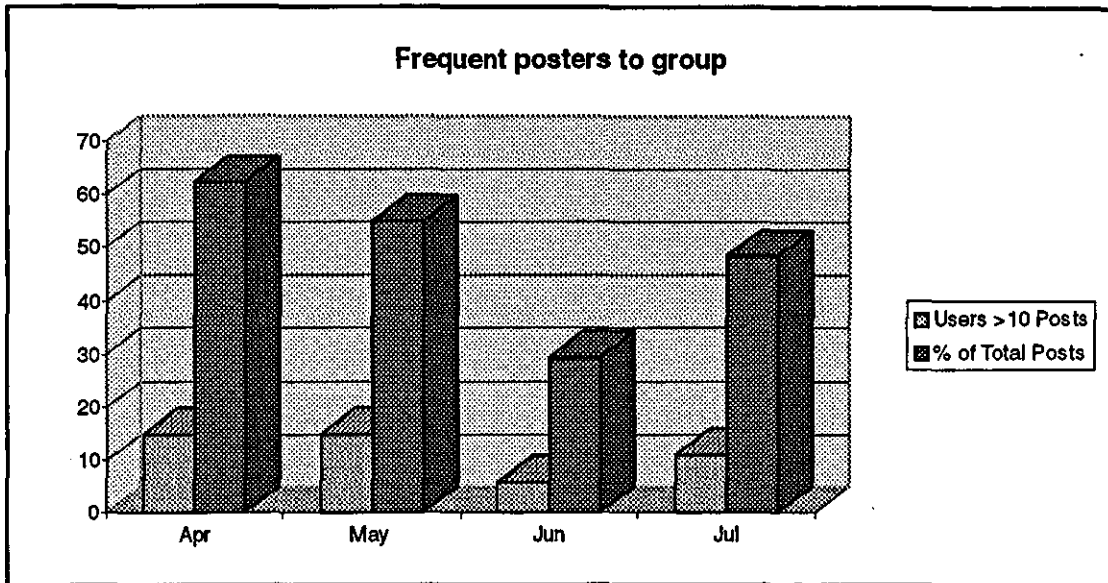


Figure 4.2. Frequent Posters to Group

Although the list contains sporadic contributions from a large majority of its members (indicative of high participation in terms of messages sent), a significant percentage of posts are sent by core group members. The list has a designated listowner and an assistant, both of whom take responsibility for matters of list administration and so post frequently and in depth. As the months pass it is possible to recognise a characteristic pattern emerging: there are two or three members who form an ad hoc unofficial “welcoming party”, taking pains to greet each new member as he/she introduces him/herself. There is a clinician-sufferer who is often called upon for an “expert” opinion [issues of authority of information sources are treated below.] Various other roles include that of “gatekeeper” to a specialist source or database, or the provider of news on a specific alternative treatment.

In terms of response percentages, in July 1997 separate threads included 88 with at least one direct reply (44.7%), with 55 out of 183 threads in June (30%), and 87 from 189 threads in May (46%). This is a very loose guide to the chances of obtaining a response, since amended subject lines affect the archiving function (these figures represent direct “Re:” subject lines only) and there is likely to be significant overlap between monthly archives, with threads spilling over into the next month. Further study is required to accurately assess how many messages are not followed up, and how significant such omissions are, since requests for specific information may reasonably be considered more vital than replies to greetings, internal administration or off-topic issues.

#### 4.6. List Disclaimers Concerning Information Content

Below is an amalgam of several disclaimers from the list host and the list owner.

No effort has been made to edit for *accuracy of information*. These posts should be regarded as conversations with friends, not as authoritative information. Please consult with your physician before making any changes to your treatment...the information has not been screened, reviewed or edited in any way...please remember that the people you meet here are speaking from their own experiences and they are not in any position to diagnose or treat your condition. Do not alter your treatment based on advice from anyone on this list, *including health professionals*, without checking with your physician first.

Although the guidance on information content is clearly articulated here, it is difficult to assess to what extent the practice of sharing information follows the disclaimer.

#### 4.7. Categories of Content Analysis

##### 4.7.1. Broad Categories

Content category	Number of posts
Narrative account of condition's impact	206
Requests for information	64
Responses to Requests	175
Expression of welcome/friendship	67
List Administration issues	47
Off-topic discussion	67
Total number of posts for month	427: a single post may contain several categories

Table 4.2. Broad Content Categories

Categories overlap to a great extent, and messages can contain several categories at the same time. The open nature of the discussions, their highly personal basis, the conversational tone their are written in, all contribute to a complex whole.



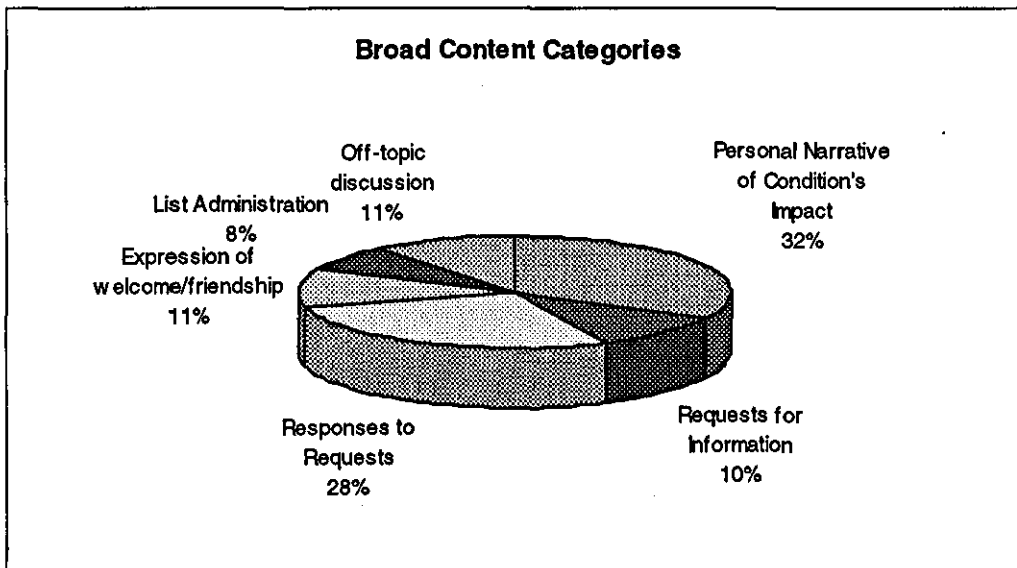


Figure 4.3. Broad content categories

#### 4.7.2. Narrative accounts

As group members themselves assert, the list's primary value lies in its members' personal experiences:

We support each other as well as we can, and sometimes it's by just being friends, and sometimes we actually have information to share. I have learned a great deal from this list, way more than from any of the books and magazines I have read.

The distinction between lay and professional perspectives is to the fore:

I knew when I joined that the information would not be from medical professionals, but I have plenty of those kind of folks already. They don't give me the information I need, though, about how to deal with having [ ] and what it means in my life.

This is underlined by the way new members are welcomed to the list and encouraged to ask questions, the overall sense being that of an extended family. The types of narrative/experiential accounts can be further subdivided:

Type of narrative/experiential content	Number of posts
General impact on life	27
Impact on family members	36
Medication/side effects	57
Nutrition & Diet	18
Statement of how the list helps	8

*Table 4.3. Types of narrative content*

Accounts often form part of an introduction by new members, many of whom have been “turking” without posting for several weeks. Parents of children experiencing the condition often use the list as a support and information resource in order better to understand their child’s condition:

Do any of you experience anything like this? I want very much to understand what she is going through [ ] but cannot, as yet, ask her to explain it to me.

#### **4.7.3. Information Requests**

Information requests mirror the types of narrative content, covering general clinical issues, specifics of medication etc. Often questions are too wide-ranging to receive any significant level of response:

I am looking for any information regarding surgery of the [ ] especially anyone with first hand experience with the surgery. I would also appreciate if anyone could point me in the direction of the better hospitals, doctors or techniques.

or form part of a follow-up to a visit to a medical practitioner:

He assured me that because the condition would have been caused by a drug it would not be permanent and my body would start to recover once I was off the drug. However, a medical book I was reading said that no matter how it started the condition was irreversible. Which is correct?

Requests for information are scattered among personal accounts and histories. Many do *not* meet with direct responses, and there should be some concern that these are not “followed up” by the list. There

may be a risk that requests are falling through the cracks, or are lost among more vibrant or controversial threads.

4.7.4. Information Responses

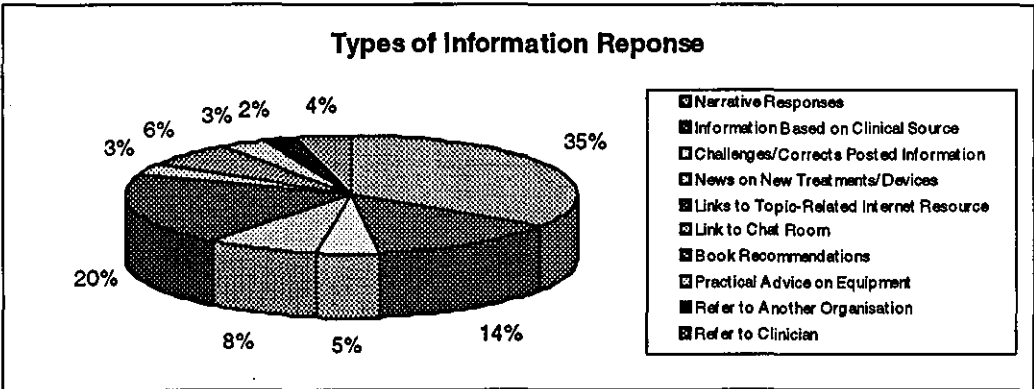


Figure 4.4. Types of Information Response

The variety of responses to requests for information highlights the differing experiences of the participants.

Responses to Information Requests	Number of Posts
Narrative Responses and opinion	60
Information Based on Summary of Clinical Source/Opinion	24
Challenges/Correction to Posted Information	8
News on New Treatments/Devices	14
Links to Topic-Related Internet Resource	35
Link to Chat Room	6
Book Recommendations	11
Practical Advice on Equipment	6
Refer to Another Organisation	4
Refer to Clinician	7

Table 4.4. Types of response

Narrative responses overlap with those accounts given as introduction or welcoming new members. Information based on summaries of clinical opinion highlights those issues around the quality and reliability of information, notwithstanding the list’s disclaimer (see above),

particularly since the largest category of information response is difficult to verify. Examples of this sort of response include:

I cannot confirm this, but [class of drugs] do stuff to your awareness in general, and [named drug] can affect moods.

But I would recommend [named drug] to anyone whose doctor suggests it. I noticed a world of changes in my moods. If you are concerned with taking [named drug] with your other meds, how about just increasing the vitamin b family...I think they are supposed to help...

Most, if not all, antidepressants REDUCE [condition effects]. They tend make the condition worse rather than better.

Information, opinion and narrative begin to elide. Sources are not quoted [but then, how often do we quote our sources in regular, free-flowing conversation?] This is characteristic of self help support activity. Personal experience is just that: it is an accumulation of information and practical advice from a range of sources which coalesce over time to form an individual's narrative of their condition and its impact on their life. If it were otherwise, it would not be self help. Members do pass on information from their practitioners, distilled and filtered by their personal context. Links to printed or WWW resources often form part of a referral response, but referral to a practitioner is infrequent. At times, particularly with something as specific as combinations of medications, dosages etc., the overall impression is of a stream of personal accounts and recommendations which, were they to be followed without clinical consultation, might prove inappropriate to an individual case. Dubious information is sometimes qualified by the list's medical professional or an academic, but the risk remains that the disclaimer is overlooked simply because the emotional and personal support is so positive. This is conjecture, of course, since it is impossible to tell how individual members respond to the information they receive.

Other information-related activities performed by the group include the building of condition-specific information resources (a drug database) and the provision of news on current research or new devices.

#### 4.7.5. List Management Issues

The group has experienced a number of controversial threads recently, and it is not intended here to further compound these difficulties. The list is undergoing a process of "moderation", whereby new subscribers are put on "review" and their posts vetted or filtered by a moderator before posting to the list. "Older" subscribers are not subject to this review at present, but a series of events in recent months have made a move to a fully moderated list more likely. This provoked some concern and led to a period of reflection on the list's purposes, by restating its inclusivity and equality but addressing the practicalities of disruptive postings (spamming) and other unwanted interventions. Several weeks later, a thread began which touched on the condition in some respects, but which some list members thought should be a side issue. Instead, it dominated postings for days, provoked emotional responses that resulted in some members unsubscribing from the list, with the list moderator threatening to close the list down for a "cooling-off" period.

This episode highlights important issues when considering Self Help Nottingham's potential role in facilitating online support groups. These can be fragile communities, and given the time-delay of postings (compared with the immediacy of typing a response) a "separation effect" was experienced. It is unlikely such a spiralling would occur in a face-to-face group, with its ability to respond to emotional exchanges as they occur, and a group experiencing such difficulties could seek a support agencies help in resolving matters. No such recourse exists in the electronic group, with increasing pressure placed on the moderator when sides are taken.

#### 4.7.6. Off-Topic Discussions

The nature of the extended family predisposes it to exchanges that go beyond discussion of the specific condition. Members offer encouragement over employment, welfare, educational and insurance issues. The way the condition is understood by society or depicted by the media is another aspect (with a strong US bias, since much of the discussion centres on US legal issues or specific broadcasts) An ongoing campaign against a large corporation has been the source for much of the list's attention (and support for the individual concerned), with the matter covered by national and state news channels.

Less focused topics (from forwarded lists of jokes to a disturbing, and unauthenticated, account of child abuse) are more prevalent than many list members have indicated they would like. The

option to set topics is an additional burden on the list moderator, and requires individual posters to specify the topic in their messages "subject" line.

#### 4.8. Conclusion

Without more detailed long-term study it is impossible to reach any conclusions about the nature or effectiveness of online support groups.

It is not possible to say conclusively that online support groups are beneficial, that they should conform to a particular model, that their exchanges should be subject to this or that intervention. Value is a context-dependent social construct, attributed by an individual person<sup>13</sup>. It is fundamentally difficult to assess the value of these electronic exchanges, since their impacts are felt by individuals in lives only hinted at through their messages.

<sup>1</sup> Rappaport, Julian. Narrative studies, personal stories and identity transformation in the mutual-help context. In: Powell, Thomas J., ed. *Understanding the self-help organization: frameworks and findings*. London: SAGE, 1994, pp. 115-116.

<sup>2</sup> Rappaport, Julian. Ref. 1, p. 124.

<sup>3</sup> Rappaport, Julian. Ref. 1, p. 129.

<sup>4</sup> Schubert, Marsha A. & Thomasina Borkman. Identifying the experiential knowledge developed within a self-help group. In: Powell, Thomas J., ed. *Understanding the self-help organization: frameworks and findings*. London: SAGE, 1994, pp. 228-230.

<sup>5</sup> Soloman, M. Content analysis: a potent tool in the searcher's arsenal. *Database*, 1993, 16(2), 62-8.

<sup>6</sup> Allen, Bryce & David Reser. Content analysis in library and information science research. *Library and Information Science Research*, 1990, 12(3), 251-262.

<sup>7</sup> Baker, Therese L. *Doing social research*. 2nd ed. New York: McGraw-Hill, 1994, 267-273.

<sup>8</sup> Ellis, D. Modelling the information-seeking patterns of academic researchers: a grounded theory approach. *Library Quarterly*, 1993, 63 (4), 477-479.

<sup>9</sup> Kramer, K.D. & K.B. Nash. Self help group models: an ecological conceptualization. In: Katz, A.H et al., eds. *Self-help: concepts and applications*. Philadelphia: Charles Press, 1992, pp. 144-148.

<sup>10</sup> Deja News - The Source for Internet Discussion Groups. (URL: <http://www.dejanews.com/>)

<sup>11</sup> Langford, D. Ethics and the Internet: appropriate behavior in electronic communication. *Ethics & Behavior*, 1996, 6 (2), 91-106.

<sup>12</sup> King, Storm A. *Researching Internet communities: proposed ethical guidelines for the reporting of results*. [unpublished.]

<sup>13</sup> Badenoch, D. et al. The value of information. In: M. Feeney & M. Grieves, eds. *The value and impact of information*, 1994, p. 16.

## Chapter 5: Self Help and the UK Consumer Health Context

### 5.1. Introduction

Self-help activity has developed in response, if not in outright opposition to, traditional models of health and welfare provision, countering the prevailing professional-centrism which views patients/clients as recipients of care rather than active participants in their own recovery. Indeed, the term “consumer” has gained increased currency in the post-1980s managerial-commercial climate of National Health Service and statutory social service policy, with self-help groups adopting the term as part of their role in “advocating for both better professional services and greater independence and control over services<sup>1</sup>.”

Self-help is thus located along a continuum of healthcare provision ranging from statutory professional services through self-care and self-treatment programmes (under professional supervision) to non-statutory provision by voluntary agencies, alternative therapists and family carers. An exploration of this wider context is important, since it will help to delineate those agencies and sectors that might form a “defined audience” for self-help support and promotion activity, thus focusing and informing any Internet strategy that seeks to involve professionals and other groups in self-help development.

### 5.2. The role of Professionals: collaboration, cooperation or co-option?

If it is the case that there is a “natural antithesis between the philosophies of self-help and professional health care<sup>2</sup>,” or that

the main impetus [to Self-help development] has been the perceived failure of professional caregivers to meet the needs of particular groups of patients...It is largely [their] freedom from professional domination that has given most groups their spontaneity, vitality, innovativeness and flexibility<sup>3</sup>.

then one might question the involvement of professionals at all, since such a presence may be seen as a threat, undermining autonomy and self-determination and “eroding the self-help group’s unique contribution<sup>4</sup>.” A more realistic approach is to recognise the possibility of professional involvement within redrawn boundaries, utilising professionals as an information resource. As Posner points out, “the Self-help modality expresses and offers the promise of a

quite contrary style of human relations, and challenges and considerably modifies the traditional professional [service delivery] role<sup>5</sup>”; such a *modification* (not outright substitution) takes place on the group’s own terms without compromising their relative informality and the intrinsic values and structure outlined above.

According to Powell, researchers must develop “valid information about self-help programs that will enable professionals to become better informed about the structural characteristics, change processes and probable outcomes for users<sup>6</sup>,” a view which centres on the role of professionals as *referrers* to self-help activity or *facilitators* of it. Participation in self-help groups can help stimulate appropriate service demand, through increased awareness of services and raised levels of confidence and assertiveness<sup>7</sup>. Partnership with professionals may also promote equality of access along social class, ethnic or geographical lines. Inefficiencies, overlap and duplication of resources can be minimised. Integration with statutory services, where sanctioned, can more readily take place. “Only when there is genuine collaboration among professionals and self-help groups, viewed as resources rather than clients, can empowerment be achieved<sup>8</sup>.” However, the fear of being co-opted by other agencies and hierarchies looms large, given the cynical possibility that self-help is developed merely as a cheap alternative to existing statutory services rather than building a complementary role.

### 5.3. National policy: vacuum or opportunity?

Those national support structures that were pump-primed in the mid- and late-1980s, namely the Self Help National Network, the Department of Health-funded Self-Help Alliance (1985-1989)<sup>9</sup> <sup>10</sup> and the recently defunct Self Help Centre of the National Council for Voluntary Organisations (1986-1995)<sup>11</sup>, represent a series of short- and medium-term initiatives aimed at tackling long-term goals. Of the seventy-eight support agencies listed by the Self Help Alliance’s 1989 directory, only nine were still running by 1995<sup>12</sup>, mostly provided by local Councils for Voluntary Service (CVS). Self Help Nottingham itself operated under the Nottingham CVS banner until April 1997.

Such ventures are more often than not hampered by the sort of uncertain funding programmes that fuel cynicism over central government’s commitment to self-help development (small funding levels at the periphery, it was hoped, would produce larger returns to offset rising social security budgets<sup>13</sup>.) Self-help emerged from the Thatcher years with its “fringe activity”



status intact, a marginalisation compounded by the lack of consistent response and self-help activity's own transience, fragility and multiplicity of aims.

Like the individuals of whom they are composed, groups have differing strengths, limitations and lifespans. An appreciation of these differences and constraints...can lead to more realistic policies with respect to this component of the voluntary sector<sup>14</sup>.

Both the NCVO Self Help Support Centre and researcher Mai Wann have examined more strategic aspects of self-help support, the latter arguing for a reorganisation of the welfare state with self-help given due prominence:

A remodelled welfare system for the 21st century should recognise self-help as a core activity - that implies understanding its strengths and limitations, organising support systems around it, and changing the ethos of statutory services<sup>15</sup>.

Such an approach is hardly inconsistent with the long-term objectives of the NHS, according to the former Conservative government's final White Paper *A Service with Ambitions*<sup>16</sup> which upholds the importance of patient independence, the provision of "information necessary to understand and take part in decisions about health" and a focus on access according to individual patient needs rather than institutional practice. Two earlier related White Papers, *The Health of the Nation*<sup>17</sup> and *Working for Patients*<sup>18</sup>, enshrine similar consumerist visions of active involvement in health promotion and social care policies, as do wider *Patient's Charter*<sup>19</sup> initiatives. Applying such thinking to the sphere of self-help leads to the argument that informed self-helpers are better placed to participate effectively in their own care, encouraged to make more effective use of health and social services. Such a view is consistent with an understanding that "self-help is about personal responsibility and interdependence. Its ethos is one of enabling people rather than being protective, philanthropic or prescriptive<sup>20</sup>." Such questions of empowerment, of knowledge as a source of power adopted by the "informed consumer" of services, of increased competence and responsibility for decisions made about their own care, encapsulate the inevitable political dimension of health and social policy. Issues surrounding the *quality* of such information, and whether the Internet in its many guises is a valid source for the type and quality of information beneficial to self-help activity, will be covered in the case studies and guidelines chapters. Such issues will always be problematic, given the creative, challenging, innovative but also complex and paradoxical nature of self help. What is aimed at is not a definitive listing of the information needs of self help groups and

their support agencies, but to establish guidelines for the identification and evaluation of beneficial resources and access strategies.

#### 5.4. A national voice for self help?

The NCVO Self Help Centre has reported concern over the conspicuous absence of a coherent national strategy for self-help support. Lack of coordination has far-reaching consequences for the targeting of direct and indirect resourcing, information dissemination and the adoption of good practice, and the duplication of support activities. "Coordination of local and national support and development systems" and the "creation of national liaison and promotion systems" are specified as functions requiring investment, in order to "market self-help activities and their impact rigorously to ensure that they take an appropriate place on the agendas of national policy makers and funders<sup>21</sup>."

Aside from complex issues of voluntary sector funding which cannot be tackled here, it is important to highlight the opportunity that now presents itself for an organisation to step into the breach and tackle two of the central issues raised by the NCVO Self Help Centre's assessment:

- to develop a national profile for self help (integration with the work of policy makers)
- to coordinate and disseminate example of good practice

Central to the argument of this thesis is a recognition that aspects of Self Help Nottingham's intention to develop as a *national centre of excellence* may be furthered by the development of an Internet strategy which addresses the challenges of national self help support and development. There is a strong functional correspondence between national aims (profile and awareness-raising) and the development of an Internet-based information strategy which is constructed around SHN's organisational aims, as will be explored through the Clearinghouse model, WWW site case studies and the practical aspects of site design and content.

<sup>1</sup> Rappaport, Julian. Narrative studies, personal stories and identity transformation in the mutual-help context. In: Powell, Thomas J., ed. *Understanding the self-help organization: frameworks and findings*, 1994, p. 133.

<sup>2</sup> Emerick, R. The politics of psychiatric self-help: political factions, interactions, support and group longevity in a social movement. *Social Science and Medicine*, 1991, 32, 1126.

- <sup>3</sup> Lock, Stephen. Self help groups: the fourth estate in medicine? *BMJ*, 1986, 293, 1596-7.
- <sup>4</sup> Hasenfeld, Y. & B. Gidron. Self help groups and human service organizations: an interorganizational perspective. *Social Service Review*, 1993, June, 234.
- <sup>5</sup> Posner, Tina. The development of self-help organisations: dilemmas and ambiguities. In: Humble, Stephen. & Judith Unell, eds. *Self-help in health and social welfare: England and West Germany*, 1984, p. 54.
- <sup>6</sup> Powell, Thomas J. Self-help research and policy issues. In: Powell, Thomas J., ed. *Understanding the self-help organization: frameworks and findings*, p. 7.
- <sup>7</sup> Powell, Thomas J. Ref. 6, p. 20.
- <sup>8</sup> Hedrick, H.L., Isenberg, D.H & C.J.M. Martini. Self help groups: empowerment through policy and partnerships. In: Katz, A.H et al., eds. *Self-help: concepts and applications*, 1992, p. 49.
- <sup>9</sup> Miller, Eric. *Support for self help: the origins and development of the Self Help Alliance*, 1987.
- <sup>10</sup> Bradburn, Jane & Peter Cartwright. *Working together for self help: the final report of the Self Help Alliance*, 1989.
- <sup>11</sup> Hyatt, Jenny & Jude England. *Investing in the heart of change: the case for resourcing the support and development of self help activities*, 1995.
- <sup>12</sup> Wann, Mai. *The development of "self help" activities [summary]*, 1995. [Social Care Summary 5]
- <sup>13</sup> Humble, Stephen. Government policy on self help groups in England. In: Humble, Stephen. & Judith Unell, eds. *Self-help in health and social welfare: England and West Germany*, 1984, pp.24-25.
- <sup>14</sup> Richardson, Ann. English self-help: varied patterns and practices. In: Pancoast, D.L. et al., eds. *Rediscovering self-help: its role in social care.*, p. 220.
- <sup>15</sup> Wann, Mai. *Building social capital: self-help in a 21st century welfare state*. London: Institute for Public Policy Research, 1995.
- <sup>16</sup> Department of Health. *The National Health Service : a service with ambitions*, 1996.
- <sup>17</sup> Department of Health. *The Health of the Nation : a strategy for health in England*, 1992.
- <sup>18</sup> Department of Health. *Working for patients*, 1989
- <sup>19</sup> Department of Health. *The patient's charter*, 1991.
- <sup>20</sup> Wann, Mai. Just help yourself. *Health Service Journal*, 1995, 26 January, 27
- <sup>21</sup> Hyatt, Jenny & Jude England. Ref. 11, pp. 10-11, 13.

## Chapter 6: Self Help Nottingham - The Project Partners

### 6.1. Background

The early development of the Nottingham-based Self Help Team (recently renamed Self Help Nottingham) has been explored by the team's founder Judy Wilson in an earlier participant action research project<sup>1</sup>, a work which built on her extensive practical experience in supporting and promoting self-help activity. Wilson's publications on self-help development and the involvement of professionals<sup>2 3</sup> have served both to underline Self Help Nottingham's national profile and to prepare the ground for subsequent development now that, following her departure, the organisation has entered a new phase as a registered charity and a company limited by guarantee. Funding is still predominantly Health Authority-derived [75% in 1995/96<sup>4</sup>], but the organisation is committed to developing and implementing "an effective strategy for fundraising and attracting resources...in order to build a stable financial base<sup>5</sup>." If the NHS is a service with ambitions, then so too is Self Help Nottingham, eager to develop as a UK centre of excellence for self help development under the banner *active alliances - working with others to achieve common goals*<sup>6</sup>. Over 200 groups are covered in the local directory published by the team<sup>7</sup>, and research has recently resulted in a national directory (*Connect Self Help UK*<sup>8</sup>) to underline SHN's national profile.

This dissertation project itself forms part of a wider organisational assessment of information needs, resources and services, coordinated by the Information Officer. There is an expressed interest in "being at the forefront of new and accessible communication methods<sup>9</sup>."

### 6.2. Information audit

The 1997/98 Workplan divides the organisation into five sections,

- Information
- Training & Development
- Administration & Finance
- Director
- Trustees

The project focuses on those information roles and communication functions that are appropriate to potential Internet initiatives. Overall, the SHN team performs a facilitatory and intermediary role between groups and health and social care professionals, the media and other agencies, offering a range of training, promotional and advisory services to new and existing groups. This is covered in greater detail in the WWW site itself [see Appendix].

The Information section performs several tasks with potential scope for Internet developments:

- maintaining a central "resource area" of self-help information, for local groups and as a national repository of published and grey literature on self help issues and research.
- promotion and publicity for the "relaunched" Self Help Nottingham
- networking with other researchers and information officers
- maintaining links with national organisations to obtain relevant information and literature
- marketing and distribution of the local and national directories
- identifying national self help-related events
- coordinating the team's e-mail and internet access
- strategy for group access

Two functions of other sections are also considered: the support and development of new and established groups, and fundraising issues.

Staffing levels correspond to the findings discussed in Chapter 7, with the emphasis on core staff (hours vary) in each section, supported by over a dozen volunteers. This structure will have a serious impact on the team's ability to implement and maintain an effective Internet strategy. It is likely that support will be required from a number of other projects related to online community infrastructure within Nottinghamshire, involving Internet Service Providers and other commercial and voluntary agencies.

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<sup>1</sup> Wilson, Judith M. *Supporting self help groups: an action research study based on the work of the Nottingham Self Help Groups Project between 1982 and 1983*. MPhil dissertation, Department of Social Sciences, Loughborough University of Technology, 1987.

<sup>2</sup> Wilson, Judy. *Good links: guidelines on how self help groups can work with professionals*. Nottingham: Self HelpTeam, 1994.

<sup>3</sup> Wilson, Judy. *Two worlds: self help groups and professionals...*, 1994.

<sup>4</sup> Self Help Nottingham. *Annual report 1995-96*, p. 2.

<sup>5</sup> Self Help Nottingham. *Annual work plan 1997-98*, p. 23.

<sup>6</sup> Self Help Nottingham. Ref. 4, p. 3.

<sup>7</sup> Self Help Nottingham. *A directory of self help and carers' groups in Nottingham and district 1996/97*. 16th ed. Nottingham: Self Help Nottingham, 1996.

<sup>8</sup> Self Help Nottingham. *Connect Self Help UK*. Nottingham: Self Help Nottingham, 1997.

<sup>9</sup> Self Help Nottingham. Ref. 4, p. 3.

## Chapter 7: Implementation of IT in the Voluntary Sector

### 7.1. The Voluntary Sector Context

An Internet strategy represents a narrower, if more idiosyncratic manifestation of a wider movement of Information Technology (IT) in the workplace, and an analysis of the Internet's potential uses benefits from this broader perspective of IT implementation in small-scale, non-commercial settings.

As work in the related field of marketing for non-profit organisations indicates<sup>1 2</sup>, the voluntary sector presents difficulties when measuring the impact on activities which do not overtly aim at economic or competitive advantage (attempts to reduce costs, increase market share etc.) and are experiential in nature. However, voluntary sector organisations are concerned with meeting a *social need* (to bring benefits to client groups, to change society or public perceptions etc.) and so adopt IT strategies, however loosely organised, in order to secure advantage in terms of improving their ability to meet that social need through enhanced services. The paradigm of competitive advantage needs re-focusing: competition *does* exist, in terms of limited funding and overlap of function with other agencies (local, regional, national and, in Internet terms, international) and in the wider context of the "information society" *inertia* itself is a form of competition.

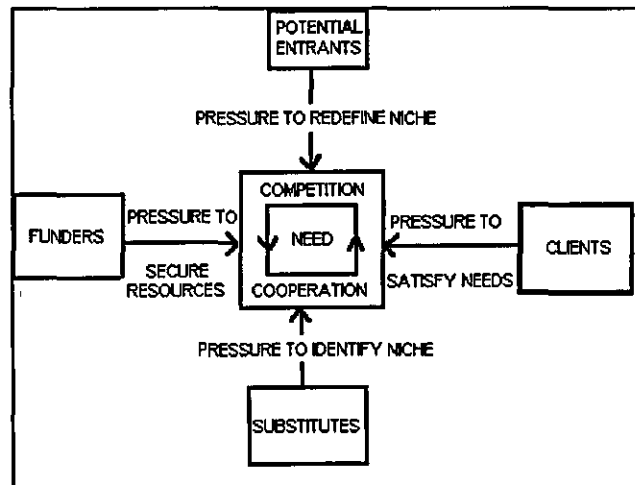


Figure 7.1. Boyle et al's redefinition of Porter's 5 forces model for the social profit sector

This research is representative of Self Help Nottingham's interest in IT to research and target a particular service (the Web Resource and its content) and to monitor a more general trend (the Internet) both for its own IT strategy and on behalf of its diverse *client groups*. Role

redefinition is important at this stage as the team adapts to its independent charitable and company status, and although *funding* is predominantly from a previously secured source (Health Authority) the pressure to secure funding for specific projects or to expand human resources is increasingly import. *Substitutes* and *potential entrants* to this specialised sector are difficult to discern at present, but may emerge in future in the shape of national initiatives centred around bodies such as the NCVO, Help for Health Trust or regional health information networks.

To be left behind at a crucial stage in the “information society’s” growth may prove costly for those organisations that attempt to remain outside its influence, whereas participation may enable the voluntary sector actively to shape the development of services and so better reflect their non-commercial ethos. The voluntary sector is not uniform, with larger professional organisations better placed to plan effectively and access information resources or political influence<sup>3</sup>, so cooperation through information network initiatives<sup>4 5 6</sup> represents an opportunity to overcome such inequalities. But even *within* organisations information use varies widely between managerial and direct service levels, making internal strategies to “cascade” skills throughout the organisation vital if over-concentration of IT skills in one function or individual is to be prevented<sup>7</sup>.

## 7.2. Generalised stage hypothesis

Phase 1 ♦ Automation of routine work for efficiency

Phase 2 ♦ Expertise and expectations rise. Management of information resources (rather than technology alone) for decision-making and analysis. Increased effectiveness

Phase 3 ♦ Radical restructuring or change of goals facilitated by IT<sup>8</sup>.

In the case of Self Help Nottingham, the organisation is moving beyond Boyle et al’s Phase 1 (the stage at which they found to be the “main focus of operation in the voluntary sector<sup>9</sup>”), having automated key functions such as Administration and Financial Planning, the maintenance of the annual group contacts directory, HelpBox and other Information functions; their progress through Phase 2 is more equivocal.

Phase 2 IT implementation moves beyond automation and links IT to organisational objectives, an ongoing interaction between the organisation and the supporting technology which provides information for decision-making purposes. Viewed as information resource management, it

involves an integrated organisational strategy for managing both the information itself and the *enabling* resources: physical tools and materials, financial investment and people. That Phase 2 is difficult for voluntary organisations to fully achieve at present is the result of constraining factors: limited time and resources, and lack of expertise and training, often compounded by poor initial selection of IT equipment. The voluntary sector contains few technocrats.

### 7.3. Self Help Nottingham IT Inventory

An inventory of Self Help Nottingham's core IT equipment gives an indication their commitment to extending IT beyond the internal operation level to the strategic.

<b>Internet Workstation</b> Gateway 200 Intel 166Mhz Pentium PC Windows 95 operating system Microsoft Office 97 Small Business Edition  US Robotics Sportster 33.6bps external modem Global [internet service provider] annual subscription Dedicated BT phone line HP Deskjet 690C+ printer  Total cost ~£2000.00	<b>Information Team Workstations (two)</b> Dell 486 PCs [8mb RAM] Windows 3.1 operating system Helpbox Quattro Pro Cardbox [maintains directory of local groups]  <b>Finance/Desktop Publishing Workstation</b> Pentium 75Mhz PC [12 Mb RAM] Windows 95 operating system Aldus Pagemaker 6.0 Quicken accounts software
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This research attempts to deepen the organisation's understanding, to provide guidelines and to highlight issues that address those managerial/technical functions so vital to the successful implementation of an Internet strategy. In so doing, the personal knowledge base within the organisation can be enhanced, and the benefits be felt more widely across the staffing structure. Such planned development is to be "phased in" as time and resources allow: any investment in IT, in terms of financial and staff resources, has to be justified by the benefits it confers on the organisation in terms of meeting its goals.

Voluntary organisations utilise IT in several strategic areas: campaigning, fundraising, dissemination, financial planning. The concept of the value chain - the stream of interdependent activities connected by linkages - is a useful one, highlighting trade-offs in efficiency terms across different functions: at Self Help Nottingham, making full-text resources available electronically could reduce publication costs and free up time and resources for promotional activity, training or research.



#### 7.4. Potential for Cooperation

With resources scarce, it is vital to reduce duplication of effort, but Boyle's survey indicated that, although "cooperation is valued highly, in IT terms there is little happening at present"<sup>10</sup>. Voluntary organisations are perhaps by their non-commercial nature quick to seize on the collaborative potential of IT without addressing the concrete ways in which this is to be achieved. Besides, a human network must first be in place before an electronic network can be grafted on to it (and as Chapter 11 indicates, a WWW presence, however content-laden and interactive in design, cannot mask a lack of real human resources on the ground.)

The caring/social ethos can translate into increased decentralisation and a general openness of structures, but it must be remembered that the users themselves will be the implementers of the new system. This study mirrored several features of Morgan's ITEM methodology<sup>11</sup>, focusing as it does on interviews to bring attitudinal factors to the surface, utilising the Information Officer as a key informant and likely "change facilitator", encouraging self-sufficiency, and asking the team to assess from their own perspective what they felt had been achieved.

<sup>1</sup> Kotler, P. & A. Andreason. *Strategic marketing for nonprofit organizations*. 4th ed. Englewood Cliffs, NJ: Prentice-Hall, 1991.

<sup>2</sup> Dibb, S. & L. Simkin. *The marketing casebook: cases and concepts*. London: Routledge, 1994.

<sup>3</sup> Habib, J. Information provision: more of the carrot cake, less of the carrot. *Assignment*, 1994, 12(4), 19-21.

<sup>4</sup> Jones, N. Charities and the need for information. *Assignment*, 1994, 12(4), 22-23

<sup>5</sup> Harris, K. Information in the community and voluntary sector. *Information Technology and Public Policy*, 1992, 11(1), 49.

<sup>6</sup> McGrath, Brid. The information workers' network: an Irish experiment in voluntary/statutory partnership. *Assignment*, 1991, 8(4), 42-44.

<sup>7</sup> Schervish, P.H. Information use by levels in human service organisations. *Computers in Human Services*, 1993, 9(3/4), 397-408.

<sup>8</sup> Boyle, A. et al. The use of IT in the voluntary sector. *International Journal of Information Management*, 1993, 13(2), 95.

<sup>9</sup> Boyle, A. et al. Ref. 8, 98.

<sup>10</sup> Boyle, A. et al. Ref. 8, 108.

<sup>11</sup> Morgan, Gareth G. ITEM: a strategic approach to information systems in voluntary organisations. *Journal of Strategic Information Systems*, 1995, 4(3), 225-237.

## Chapter 8: The Self Help Clearinghouse Model

### 8.1. Context

The term “self-help clearinghouse” gained recognition in the early 1980s largely through the work of American agencies and is linked to the notion of “I & R” or “Information & Referral” services. One of the field’s leading commentators, Edward Madara, has subsequently extended the model, in a number of practical forms, from the early computerised database of the New Jersey Self-Help Clearinghouse (serving a state population of 7,500,000<sup>1</sup>) to a fully-fledged Internet-based American Self-Help Clearinghouse website and the associated Self-Help Sourcebook Online<sup>2</sup> (see later evaluation of this site) Notwithstanding these two decades of technological advance, the principles underlying US clearinghouse activity have remained constant, and comparison with Self Help Nottingham’s organisational structure and range of services will illustrate that, terminology aside, there is a great deal of common ground and scope for comparative analysis.

Clearinghouses serve self-help groups through coordinated activity to

- increase “awareness, use and development of [groups] in their communities<sup>3</sup>”
- serve as an interface between self-help groups and other organisations, populations, professionals and the public<sup>4</sup>
- liaise with human service professionals to develop referral linkages and educate professionals to appreciate the benefits and sensitive nature of self-help activity
- promote access to self-help by identifying and referring enquirers to groups as part of an “information and referral” service<sup>5</sup>
- compile, update and distribute directories or listings of self-help groups within a defined geographical area
- provide guidelines, development strategies and advice on starting a group or extending existing group activity
- facilitate networking between groups<sup>6</sup>
- promote, publicise and raise awareness of self-help activity
- carry out or sponsor research into Self Help (e.g the structure and characteristics of groups: longevity, membership profile, leadership, activities etc. )
- develop current awareness services to further self-help research

This combination of information dissemination, education, advocacy and professional bridge-building is underlined by the concept of a “demonstrational effect”<sup>7</sup> a process which encourages initial “help-seekers” to become “resource developers”, establishing their own groups when needs are not being met by existing provision.

Lay persons were much more likely to start a new self-help group...if they could be encouraged with evidence that others had started a similar group elsewhere<sup>8</sup>.

It is this “community resource-building capability” that clearinghouses attempt to tap into, serving as a focus for local activity and national policies aimed at extending self-help. As Meissen indicates, such support itself requires further research:

professionals would view the activities of the clearinghouse, and self-help groups in general, in a more positive light if information could be provided that documents the impact of clearinghouse activities and the usefulness of self-help groups<sup>9</sup>.

Clearinghouses as organisations are ideally placed to carry out such “action research”, based on their access to groups, the mutually beneficial nature of such feedback and assessment, and their sensitivity to groups’ needs with respect to autonomy and self-determination. Such research must take into account a social exchange relationship in order to minimise the perceived cost of participation and to maximise the perceived benefits, a process that is likely to run more smoothly given the trust between support agency and groups and their supportive, non-confrontational approach.

## 8.2 The Electronic Clearinghouse: early approaches

Madara’s coordination of early computerised systems in New Jersey developed in step with his growing national profile through involvement in the early bulletin board services (BBSs) and community networks such as Fidonet, and Compuserve forums (located on commercial online hosts.) Before the Internet gathered momentum, characterised by the exponential growth of its World Wide Web component, terms such as “teleconferencing via computer” or “alternative community networks”<sup>10</sup> were deployed to express the hope that self-help support and referral activity could be conveyed by electronic means.

As early as 1985 Madara wrote "the networking capability of a self-help clearinghouse offers a unique opportunity to use IT to...create support services where none currently exist<sup>12</sup>," often as a result of low prevalence (e.g. a rare syndrome or disorder) or geographical isolation (e.g. rural communities.) Such a vision is founded on the belief that "electronic communication will increase the linkage of people, ideas, concerns, while providing many innovative ways for people to find and develop the mutual aid and support they need<sup>13</sup>" and is grounded in a "natural cycle of change: network - organise - educate - advocate."<sup>14</sup>

The practicalities of this model of the personal networked computer as empowering tool will be analysed later, but it is vital to note here the *direct evolution* of self-help clearinghouse activity through early networks to the present World Wide Web manifestation and related services. Support activity seems to be particularly fertile ground for IT development, with the Internet representing part of this wider process of the introduction of IT in the human/social services.

As the following chapter will demonstrate, Self Help Nottingham can be compared within the frame of reference developed by various phases of US self-help clearinghouse transformation, underlining the importance of an analysis of more recent Internet initiatives across the Atlantic within a context of "best practice", selecting those aspects that are likely to prove more beneficial to UK self-help development. Sensitivity to the local context is as vital to work with individual groups and communities as it is to more strategic work with self-help support agencies.

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<sup>1</sup> Madara, Edward J. The self-help clearinghouse: tapping the resource potential of I & R services. *Information and Referral*, 1985, 7 (1), 48.

<sup>2</sup> American Self-Help Clearinghouse. *Self-help sourcebook online*. (URL: <http://www.cmhc.com/selfhelp/>), 16 July 1997.

<sup>3</sup> Madara, Edward J. Supporting self-help: a clearinghouse perspective. *Social Policy*, 1987, Fall, 28.

<sup>4</sup> Meissen, Gregory J. & Mary L. Warren. The Self-help clearinghouse: a new development in action research for community psychology. In: Powell, Thomas J., ed. *Understanding the self-help organization: frameworks and findings*, 1994, p. 191.

<sup>5</sup> Wollert, Richard. An information and referral model for improving community utilization of self-help groups. *Information and Referral*, 1985, 7 (2), 1-16.

<sup>6</sup> Madara, Edward J. Mutual aid self-help on-line: the new telecommunities. Paper presented at the International Conference on Computer Technology and Human Services in the 90s: HUSITA 2, Rutgers University, New Jersey. June 29th 1991

<sup>7</sup> Madara, Edward J. Ref. 1, 47.

<sup>8</sup> Madara, Edward J. Ref. 3, 28.

<sup>9</sup> Meissen, Gregory J. & Mary L. Warren, Ref. , p. 197.

<sup>10</sup> Madara, Edward J. The primary value of a self help clearinghouse. In: Katz, A.H et al., eds. *Self-help: concepts and applications*, 1992, p. 121.

<sup>11</sup> Madara, Edward J. Ref. 1, 54.


<sup>12</sup> Madara, Edward J. Ref. 3, 29.

<sup>13</sup> Madara, Edward J. Ref. 11, p. 124.

## Chapter 9: Evaluative Case Studies of WWW Sites - UK

### 9.1. Northern Advisory Group on Disability<sup>1</sup>

The Northern Advisory Group on Disability (NAGD) is an umbrella organisation charged with promoting the more efficient working of more than 500 disability-related voluntary groups in Tyneside. Communication and networking at the regional level was proving problematic as a result of geographic dispersal. The telematic pilot scheme launched in 1996 and implemented by Tagish Ltd<sup>2</sup>, concentrates on the brokerage function of groups by providing a mechanism for information exchange. Eight groups were provided with modems and Internet dial-up accounts (£2,000 per group set-up costs), and Lotus Notes databases have been devised for the groups to input information on publications, contact points and forthcoming events which is then published on the central web site. Local databases are replicated from a central server so that each local group can access the total content of the pooled databases from its own server. The relatively low cost (£20,000 through RADAR funding) is shared by all groups. User interfaces are simple and robust, and the pilot is set to be extended to another 50 groups by the end of 1997.

<b>Northern Advisory Group on Disability</b> 	<b>Directory of Self Help and Support Groups 1997</b>
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Welcome to the Tyneside Directory of Self-Help and Support Groups compiled and published by Health Action in conjunction with Gateshead Council on Disability, North Tyneside Voluntary Organisations Development Agency and South Tyneside Community Health Council.

The Directory is organised into three main areas; A Full A - Z listing of the groups; Listing by Main Subject Areas and by Regional Listing. Also provided are some information about the Self Help Group, Using this directory, Acknowledgements and Additional Information.

→ [A Guide to Using the Directory](#)

→ [A -Z Listing of Groups](#)

→ [Groups Listed by Location](#)

→ [Groups by Main Subject Area](#)

→ [Information About Self Help](#)

→ [Additional Information and Acknowledgements](#)

→ [Return to the Northern Advisory Group on Disability Website](#)

Figure 9.1. NAGD: Home Page

This framework has established an electronic presence for voluntary groups in the North East alongside that of local authorities and healthcare providers, and is represents preparation for the oft-vaunted Information Society access points in public libraries and council offices.

Coordination at the regional level combats the risk of duplication of effort and resources, and its exponents believe it to be “a scaleable, transplantable solution for the voluntary sector<sup>3</sup>”.

The NAGD site “hosts” the *Tyneside Directory of Self Help and Support Groups 1997* database. The Tyneside directory corresponds with Self Help Nottingham’s own aim to “bridge the gap between the groups which have been set up to provide help and advice and the people who may need that support<sup>4</sup>.” Published by Health Action in conjunction with Gateshead Council on Disability, North Tyneside Voluntary Organisations Development Agency and South Tyneside Community Health Council, the Directory is organised into three main areas:

- a full A-Z listing of the groups
- a listing by main *subject* areas (including Addiction, Cancer, Bereavement, Disability, HIV/AIDS, Palliative Care, Sexuality)
- a regional listing by *location*.

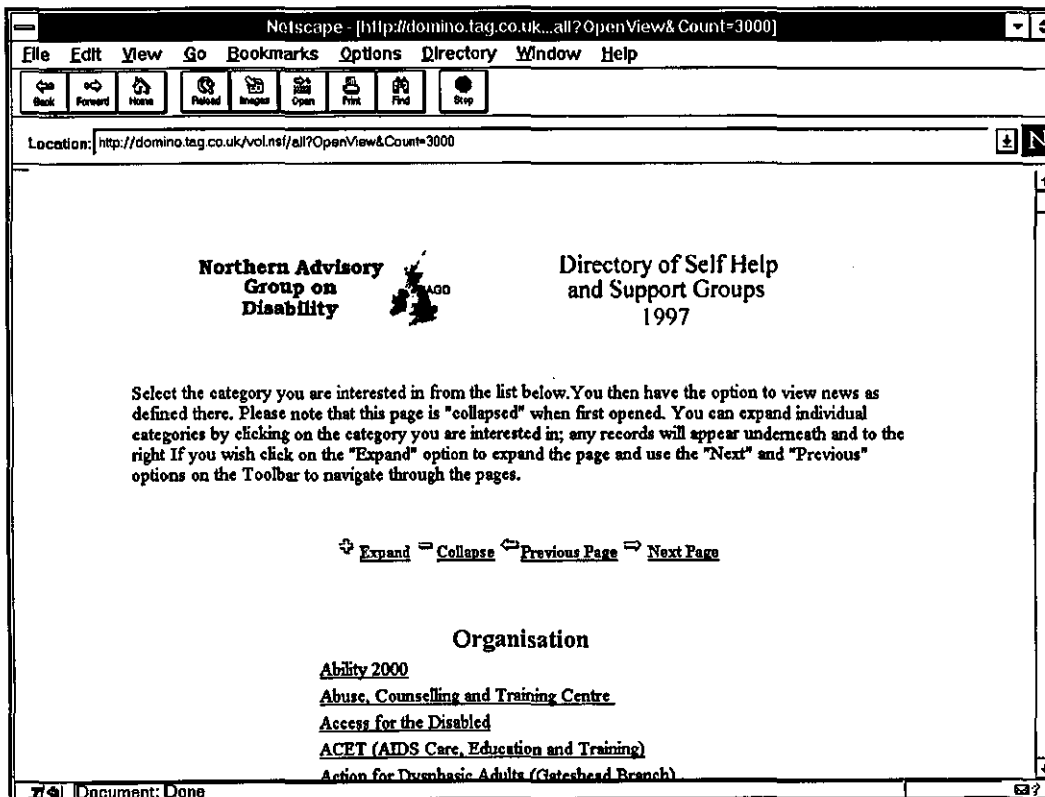


Figure 9.2. NAGD Alphabetical Group Listing

The coverage extends well beyond the emphasis on disability one might imply from the NAGD banner and includes voluntary organisations covering health and social welfare in its

widest sense. Criteria for inclusion include access by the local public (with or without professional referral), provision of information, advice and/or support, non-profit status and independence from local council or health authorities. Groups confirmed the accuracy of the content during November/December 1996. In addition to the directory, characteristics of Self Help are briefly described.

The individual group records are given in a standard format

- Contact name
- Address
- Local telephone (Voice, Minicom, Ansaphone, Fax)
- National telephone
- Three-line description of group focus/purpose/aims

Disability

and Support Groups  
1997

**Fibromyalgia Support Group (NE)**

Contact: Ms Scott MacLean

Address: 1 Lyndon Close, East Boldon, S  
Tyneside, NE36 0NT

Local Telephone: 536 9132 (voice & fax),

National Telephone:

We are a support group for people with Fibromyalgia, a chronic condition of wide-spread pain and profound fatigue. Offers a telephone advice service and monthly support meetings for people with Fibromyalgia and their families. Can provide information on the condition. The Honorary President of the Society is Dr C D Holland MB, FRCP (ED), FRCP (LOND).

[Return to Directory Homepage](#)

Figure 9.3. NAGD Single Record Display

Overall navigability of the directory is poor. It is not immediately apparent what the benefits of the expand/collapse view are, the instructions are not particularly clear. On occasion there seemed only a cumbersome single A-Z listing that takes some time to re-load each time, since there is no other way to return to the initial list of groups. On other occasions the list was divided into an alphabetical section of thirty groups to a page. It would be better to subdivide into a menu/toolbar-selectable sections (A-E, F-L etc.) or better still to utilise a local front-end search facility (cf. the Illinois Coalition, American Self-Help Clearinghouse, and Health Education Board for Scotland sites)

The directory should also allow browsing within record display mode. At present, only one full group record is shown at a time, and the previous list must be returned to in full each



time, a lengthy process. Browsing is all the more vital given the breadth of the subject divisions ("Health" and "Health Project" are not subdivided further, but contain an alphabetical list of all condition-related groups.) For example, groups listed only by acronym (CHIN-UP, BLISS etc) do not reveal their subject focus, so a simple listing under "Health" is of no assistance. More *specificity* in indexing is required, given the detail and ease of reference one would expect from a printed directory of this sort. A search engine would overcome some of these problems, providing the display mode allowed browsing forward and backward within a group of results, the overall result being greater accuracy of recall.

A further unforeseen but telling eccentricity is shown by those groups whose *local* contact number is given as the *national* 0800 665544 Health Information Service number, which would be routed to the NorthEast centre for those using the service within its boundaries. However, the NAGD Directory is now available (inter)nationally through the Internet, raising the possibility that users outside the NorthEast will attempt to contact the group, be routed to their own 0800 service who will in all likelihood be unaware of the group's existence. Such intricacies underline those questions of audience definition in the new medium.

Such drawbacks, however integral to the site's long-term success, should not detract from the pioneering work and strength of vision the directory of represents. Constructive criticism would be easily avoided by inactivity, so it is only fair that the NAGD's efforts be recognised for their innovative qualities and commitment. Above all, it should be noted that no other organisation in the UK has attempted to build a web-interfaced Self Help directory, Tyneside's example hopefully offering encouragement to other organisations that seek to do so.

The Tyneside Directory offers a tangible model around which Self Help Nottingham's own online directory can be planned. The parallels are self-evident: target audience (individuals, their relatives, friends, carers and professional staff), organisational function, an existing printed directory, and the development of a wider Internet strategy. Taking account of the drawbacks listed above, and those design and structure processes that would alleviate them, the NAGD example should be pursued further.

## 9.2. HEBSWEB<sup>5</sup>

The Health Education Board for Scotland Website (HEBSWEB) appears to have been designed by a sci-fi collective. It is hard to equate the spinning logos and purple chrome menu bars with the slightly more serious topic of health promotion. The overall effect is that of being at the controls of a space ship. If the Hollywood-inspired title page offered a "no frames" option it was lost in the outer reaches. One wonders if the questions "Who is our target audience?" and "What type of computer are they likely to have access to?" ever arose when the site was planned.

However, if the address is obtained as a link through OMNI, one might chance upon the low graphics/no frames version. However, this site does not offer the search facility of the "full" version, based on the misconception that "no frames" precludes the use of search engines. Whether or not a browser supports frames should not determine the *quality* of access to facilities offered nor its overall structure. Nor does the "low graphics" version divide the site into Public and Professional sections, yet HEBSWEB states "[on the] professional site..you can also access information not available on the public site and search all HEBS databases." On what grounds is the site split? The argument appears to be ease of use - the public being less experienced - and familiarity. It is not clear how the public are supposed to be accessing the site, nor why more graphics make the site easier for them to navigate. This is hardly consistent with the probability that public libraries will be the focus for public access: will they have the quickest machines and the most up-to-date browsers?

The Public section is subdivided into health promotion topic areas centred around campaigns (smoking, stroke, cancer, diet etc.) which then link to HEBS guides, factsheets, journal articles, posters, statistics and *support groups*. The InMagic DB/Text Webpublisher database of support groups automatically runs a search and displays results. At first glance these are, logically, Scottish in emphasis, but a large number of national organisations and associations are also included. I could find no criteria for inclusion in the database, a worrying lack of clarity. The retrieval software was fast and the display mode clearly presented with results appearing in blocks of 10.

The Professional section allows searching across the Support Groups, Journal articles, Health information leaflets, Scotland's health statistics and Scottish HIV & AIDS Initiatives Register (SHAIR) databases. Support groups can be searched by name, location, keyword or across all fields, but the engine does not allow Boolean or truncation. Groups with e-mail addresses can

be "mailed to" direct from the site. The frames version (the only version with an engine) is particularly unforgiving when trying to correct mistakes using the "back" browser arrow: relaunching a search is cumbersome.

**CONTACT GROUP**  
 Mary Loudon Chairperson/ Contact  
 30 Primrose Crescent  
 Woodburn  
**DALKEITH**  
 Midlothian  
 EH22 2JR  
 Tel: 0131 663 4633  
 Hours: 7pm-9.30pm Thurs  
 Self-help group for women suffering from anxiety and phobias. Meetings are held at the Orchard Centre, 14 Lothian Street, Bonnyrigg. Covers the Midlothian area. Transport can be provided

**MENTAL HEALTH / ANXIETY / PHOBIAS/ WOMEN/**

Last updated: 10/03/97

**CONTACT POINT WOMEN ONLY DROP-IN SERVICE**  
 Bernie or Jackie Contact Point Organisers  
 67a York Place  
**EDINBURGH**  
 EH1 3JD  
 Tel: 0131 557 3239 / 556 9960 Fax: 0131 556 0893  
 Hours: 10.30am-4.30pm Fri  
 Staffed by paid worker and volunteers. Self advocacy self-help focus.  
 Provides: advice, support, information, and if appropriate support groups would be set up.

**WOMEN/ SELF HELP GROUP/**

Last updated: 14/03/97

Retrieval software: DB/Text WebPublisher, provided by **INMAGIC**

Figure 9.4. HEBS Support Group Database Display

For all its faults, the site potentially offers a strong regional basis for the dissemination of information about groups. That so many issues of access and clarity have not been addressed means this potential remains unfulfilled at present.

### 9.3. National Institute for Social Work<sup>6</sup>

Although not involved directly in the promotion of self help, the NISW nevertheless offers illuminating parallels in the way it has harnessed the Internet to further its national ambitions, to disseminate high-content materials to voluntary sector and health/social care professionals and to act as a focus for wider developments in Internet strategies for voluntary organisations. Mark Watson, the site's primary contact, has also published in the information sciences professional literature<sup>7</sup>, which serves to underline the relevance, validity and authority of his organisation's campaigning efforts.

Clear and easy to navigate, well indexed, regularly updated, low-graphic and high-content in emphasis, the site is an excellent example of a voluntary organisation that has developed a

well-defined Internet strategy before launch. The incorporation of a mission statement beneath the opening logo clarifies the organisation's aims, and all contact details are clearly presented. But it is in the degree of content that the site impresses. This includes free access to:

- A database of current research in the UK personal social services, in collaboration with the Social Services Research Group: the site has a detailed online entry form for submitting project details. The first entries are already available on the site, arranged by topic with full contact details, scope of research and methodology.
- The Caredata CD-ROM: full-text samples are available, including abstracts on elder abuse, a full text Joseph Rowntree Finding, a search on child protection, and a full text Department of Health Circular.
- A sample of the monthly Caredata Abstracts current awareness service (more recent months are available in the Members' Section)
- Contents pages for International comparative social work research
- 23 full-text NISW Briefings (of particular relevance is *The Voluntary Sector and the Internet*<sup>8</sup>)
- Full-text publications (e.g. *Options for Long Term Care*<sup>9</sup>, a 1996 report in conjunction with the Nuffield Institute) and newsletters

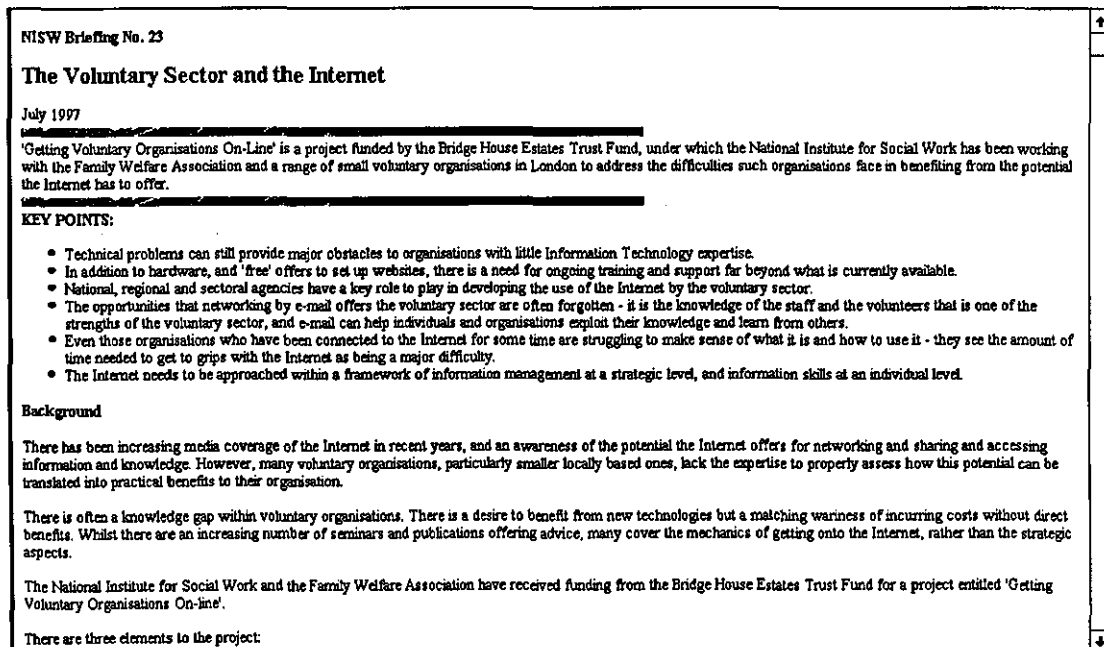


Figure 9.5. National Institute of Social Work: Full Text Resources

That the NISW is committed to furthering the use of the Internet in the voluntary sector is manifest in its London-based training and seminar programme *Getting voluntary organisations on-line*<sup>10</sup> in association with the Family Welfare Association. This attempt to

bridge a sizeable “knowledge gap” mirrors the scope of this dissertation project, with a similar strategic emphasis. Its position paper is eagerly awaited, as is the longer-term British Library Research and Innovation Centre-funded project *Digital Libraries, Special Libraries and Practitioners*.

A list of links to UK-targeted Internet resources for the voluntary sector is also included, covering voluntary organisations, academic research centres, local & central government, and health and social care electronic journals. A telling statistic is the limited links to US sites: they number only four.

As further developed in the Site Design chapter, the NISW site raises key issues about the free availability of previously charged-for materials, and the designation of a password-protected “members section” which may involve subscription or be open to existing Institute members. Both these areas touch directly on the Self Help Nottingham site and the groups wishes to develop a “friends of SHN” scheme or subscription-based equivalent.

#### 9.4. UK Primary Care<sup>11</sup>

Targeted at primary care practitioners, the site is notable for its off-putting opening “reception” section and the low-quality graphics. It is cited here because it represents the sort of site that could be targeted by Self Help Nottingham to raise awareness of their site among GPs and nursing staff, along with the mailbase list *gp-uk*<sup>12</sup>, and sites such as the National Association of Commissioning GPs<sup>13</sup> and the *Nursing and Healthcare Resources on the Net*<sup>14</sup> collection.

UK Primary Care contains a list of addresses of “Self help and advice agencies”, which is curiously available only through the password-protected “registered members” section (despite the clear indication on the home page of a “public access” area). It is a curious amalgam of trusts, societies and information centres (compiled by a single GP) and no criteria for exclusion or inclusion are given. Relevance, currency and validity are immediately called into question. This is just the sort of source that the Internet needs less of: without clearly stated scope and purpose, it is the equivalent of vanity publishing, however good its author’s intentions.

useful addresses

Addresses of Self Help and Advice Agencies

This list compiled by Dr. Andrew Minnagh & reproduced with his permission

**Aberdeen Drug Information Centre**  
Aberdeen Royal Infirmary, Forester Hill Site, Aberdeen, AB9 2ZB  
Tel: 01224 840571  
Notes: Drug Information.

**Accept Services UK**  
724 Fulham Road, London, SW6 5SE  
Tel: 0171 371 7477  
Notes: Alcohol Abstinence based counseling

**Accept: Ethnic Alcohol Counseling**  
Holdsworth House, Staines Road, Middlesex, TW3 3HU  
Tel: 0181 577 6059

**Acne Support Group**  
Hammersmith Hospital, 150 Du Cane Road, East Acton, London, W12 0HS  
Tel: 0181 743 2030

**Action for ME**  
P.O. Box 1302, Wells, Somerset, BA5 2WE  
Tel: 01749 670402  
Notes: Helpline

**Action on Pre Eclampsia(APEC)**  
31-33 College Road, Harrow, Middlesex, HA1 1EJ  
Tel: 0181 873 2400

Figure 9.6. UK Primary Care: Address List of Self Help and Advice Agencies

## 9.5. National Council for Voluntary Organisations<sup>15</sup>

The NCVO is of particular relevance to self help policy, since its now defunct Self Help Support Centre was an important national-level policy body. There is a degree of market/competitor intelligence to be obtained by monitoring its movements. Its site, however, pales in comparison with the NISW site.

Brief press releases are the only full-text sources, and beyond details of publications and services there is little else of substance. The site is inconsistent in design: the Services section suddenly jumps to frames and javascript, whereas the earlier sections are very basic text. For a national organisation, the site fails to adequately reflect the NCVO's status as an umbrella organisation for the voluntary sector. The host site, the VOIS<sup>16</sup> (Voluntary Organisations Internet Server), is similarly confusing in its layout.

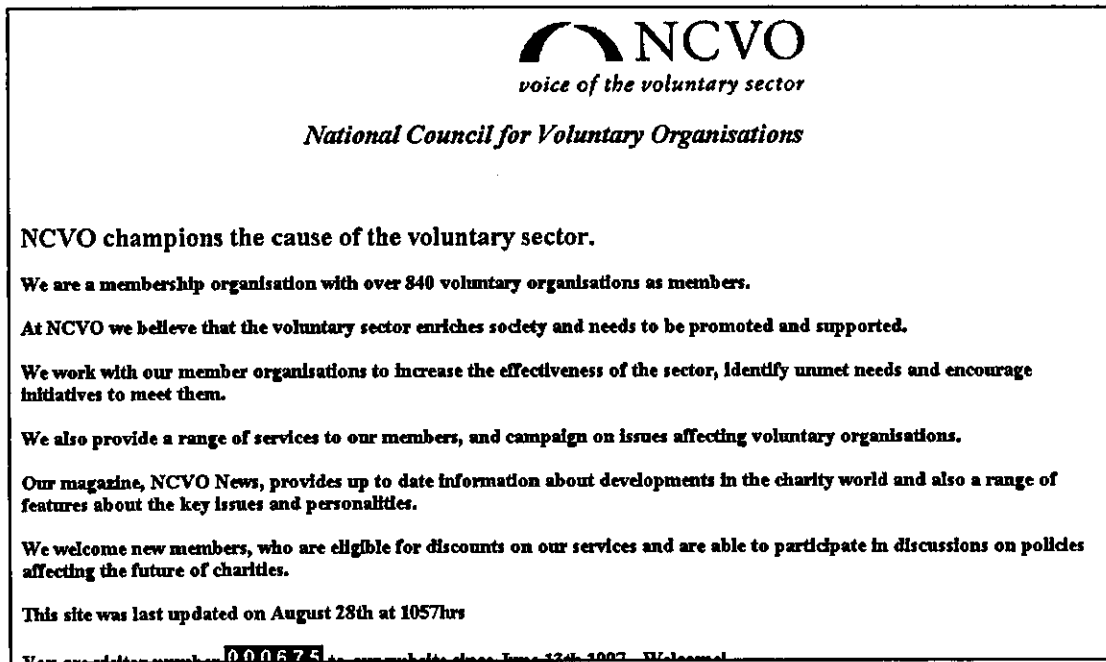


Figure 9.7. NCVO: Home Page

## 9.6. Help For Health Trust<sup>17</sup>

Help for Health Trust are already indirectly involved in Self Help Nottingham's IT implementation, since it provides the *Helpbox* software that drives the database to which the team contribute regional group details via Trent Healthline.

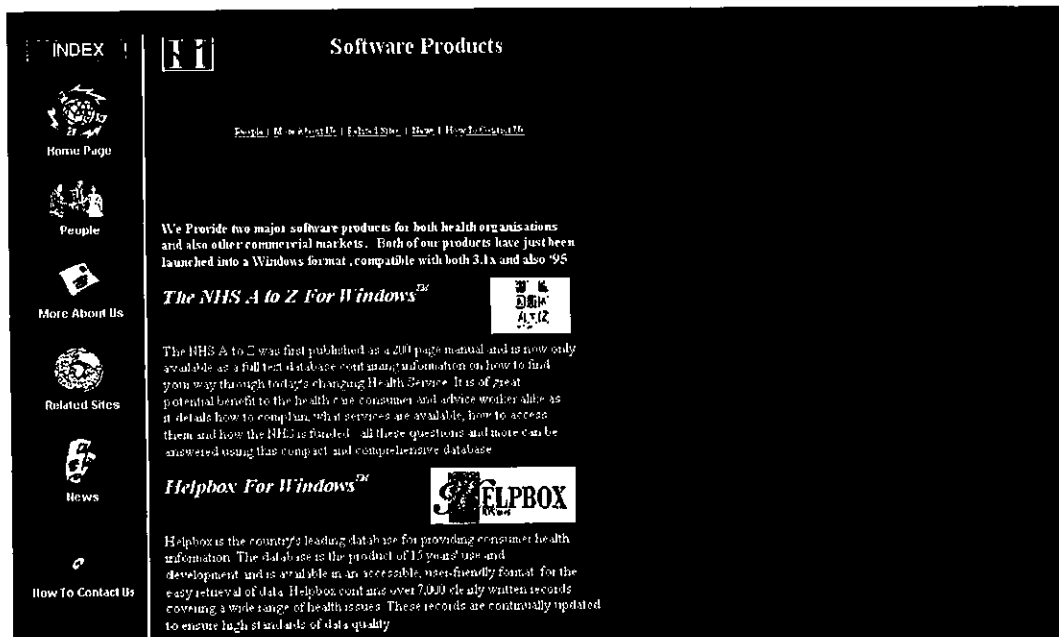


Figure 9.8. Help for Health Trust

The site is little more than a limited promotional vehicle with some basic health-related links, but may prove useful for obtaining information on updates to software, for communicating with HFHT direct, and more strategically in market intelligence terms. The market for a national self help centre of excellence may be relatively open at present, but HFHT is one organisation that already has a basis from which to fill the policy vacuum.

### 9.7. Cambridgeshire County Council: Community Information Database<sup>18</sup>

As an example of the type of local authority-resourced community networking project that promises to extend Internet-based services to the general public through libraries, schools and information points etc., Cambridge Online City's database is simple to search but lacks detail. For example, the record for a local branch of the British Epilepsy Association gives a local name and telephone number and only partial contact details for the national body.

[Home](#)   [Back to Cambridge Online City](#)   Cambridgeshire County Council  
[Back to Living and Working in Cambridgeshire](#)

### Community Information Database

Subject:

Welcome to the Community Information Database from Cambridgeshire County Council. This contains details of over 5000 local community, voluntary and self-help groups, clubs and societies, and other local resources and facilities. To search the database simply type in simple key words describing the subject you are interested in, or the first few letters of the subject name then press return, or click on "Start search".

For example: *Alzheimer's Disease, Football, Halls for hire, Parents*

[Changes to the database?](#)   [More advanced queries](#)

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**Advanced Queries.** You can also link through to a more sophisticated version of the same database, which allows searching in more complex ways: not only by subject, but

Figure 9.9. Cambridgeshire County Council: Community Information Database.

There are no scope or purpose notes (c.f. the NAGD database above), and the "venue" section often only reads "meetings in members' homes". As such, the web database serves as a telephone directory. There is a telnet version with advanced features (limit search to broad group category or location.)

<sup>1</sup> Northern Advisory Group on Disability. *Directory of self help and support groups 1997*. (URL: <http://www.nagd.org.uk>), 2 September 1997.



- <sup>2</sup> **Tagish Ltd.** *Home page*. (URL: <http://www.tagish.co.uk/tagish/>), 10 September 1997.
- <sup>3</sup> **Smith, Simon.** Telematic solutions for voluntary groups. *ETHOS newsletter*, 1997, 5, 20-21. (URL: <http://www.tagish.co.uk/ethos/newslett/issue5/>), 2 September 1997.
- <sup>4</sup> **Northern Advisory Group on Disability.** *Directory of self help and support groups 1997*. (URL: <http://www.nagd.org.uk>), 2 September 1997.
- <sup>5</sup> **Health Education Board for Scotland.** *HEBSWEB*. (URL: <http://www.hebs.scot.nhs.uk/menus/noframet.htm>, or URL: <http://www.hebs.scot.nhs.uk/>), 10 September 1997.
- <sup>6</sup> **National Institute for Social Work.** *Home page*. (URL: <http://www.nisw.org.uk/>), 16 July 1997.
- <sup>7</sup> **Watson, Mark.** Why should you be on the Net? *Library Association Record*, 1996, 98 (11), 578-9 & 581.
- <sup>8</sup> **National Institute for Social Work.** *The Voluntary Sector and the Internet* (URL: <http://www.nisw.org.uk/polb/fulltext/niswb23.html>), 12 September 1997.
- <sup>9</sup> **National Institute for Social Work.** *Options for Long Term Care*. (URL: <http://www.nisw.org.uk/pubs/options.html>), 12 September 1997.
- <sup>10</sup> **National Institute for Social Work.** *Getting voluntary organisations on-line*. (URL: <http://www.nisw.org.uk/fwa/fwa.html>), 16 July 1997.
- <sup>11</sup> **UK Primary Care.** *Home page*. (URL: <http://www.ukpc.org/>), 2 September 1997.
- <sup>12</sup> **GP-UK.** *List details*. (URL: <http://www.mailbase.ac.uk/lists-f-j/gp-uk/>), 2 September 1997.
- <sup>13</sup> **National Association of Commissioning GPs.** *Home page*. (URL: <http://www.ncl.ac.uk/~nphcare/GPUK/comiss/nacgp.htm>), 2 September 1997.
- <sup>14</sup> **Nursing and Healthcare Resources on the Net.** (URL: <http://www.shef.ac.uk/~nhcon/>), 2 September 1997.
- <sup>15</sup> **National Council for Voluntary Organisations.** *Home page*. (URL: <http://www.vois.org.uk/ncvo/>), 10 September 1997.
- <sup>16</sup> **VOIS: Voluntary Organisations Internet Server.** *Home page*. (URL: <http://www.vois.org.uk/>), 2 September 1997.
- <sup>17</sup> **Help for Health Trust.** *Home page*. (URL: <http://www.hfht.demon.co.uk/index.html>), 2 September 1997.
- <sup>18</sup> **Cambridge Online City.** *Community information database*. (URL: <http://www.camcnty.gov.uk/infosearch.html>), 2 September 1997.

## Chapter 10: Evaluative Case Studies of WWW Sites - North America

### 10.1. The Self Help Network of Kansas<sup>1</sup>

The Self Help Network of Kansas provides an object lesson in how to present clear, comprehensive information on self-help support and development issues to an international audience. Regularly updated (its most recent addition being the pull-down index menu), the overall impression is of a well-targeted, logically organised and highly navigable site whose emphasis is placed on content and the provision of referenced information. Its authority and validity are reinforced by the centre's academic status as a program of the Department of Psychology at Wichita State University (on whose website it is located). This psychological remit, however, does not skew the content of the site, which is predominantly health and social care-based.

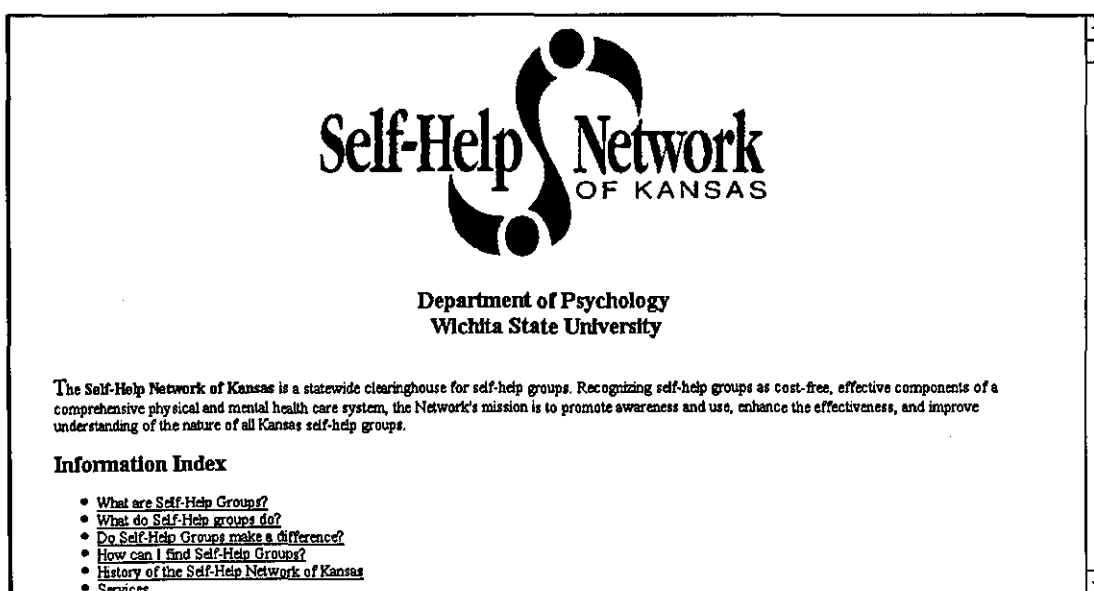


Figure 10.1. Self Help Network of Kansas: Index

A nonprofit, statewide clearinghouse organization, SHNOK has nevertheless developed a resource that looks well beyond the state it serves through its *Connections* directory of 2,140 Kansas self-help groups and 860 national self-help organizations (not available online) and presents important parallels with the organisational objectives of Self Help Nottingham. Note the resonance in its mission statement:

Recognizing self-help groups as cost-free, effective components of a comprehensive physical and mental health care system, the Network's mission is to promote awareness and use, enhance the effectiveness, and improve understanding of the nature of self-help groups.

As a model, this holds more potential than the American Self-Help Clearinghouse, to which it provides a link. Its resources are focused on self helpers and medical professionals, but its depth of coverage make the site valuable for wider support agencies and researchers.

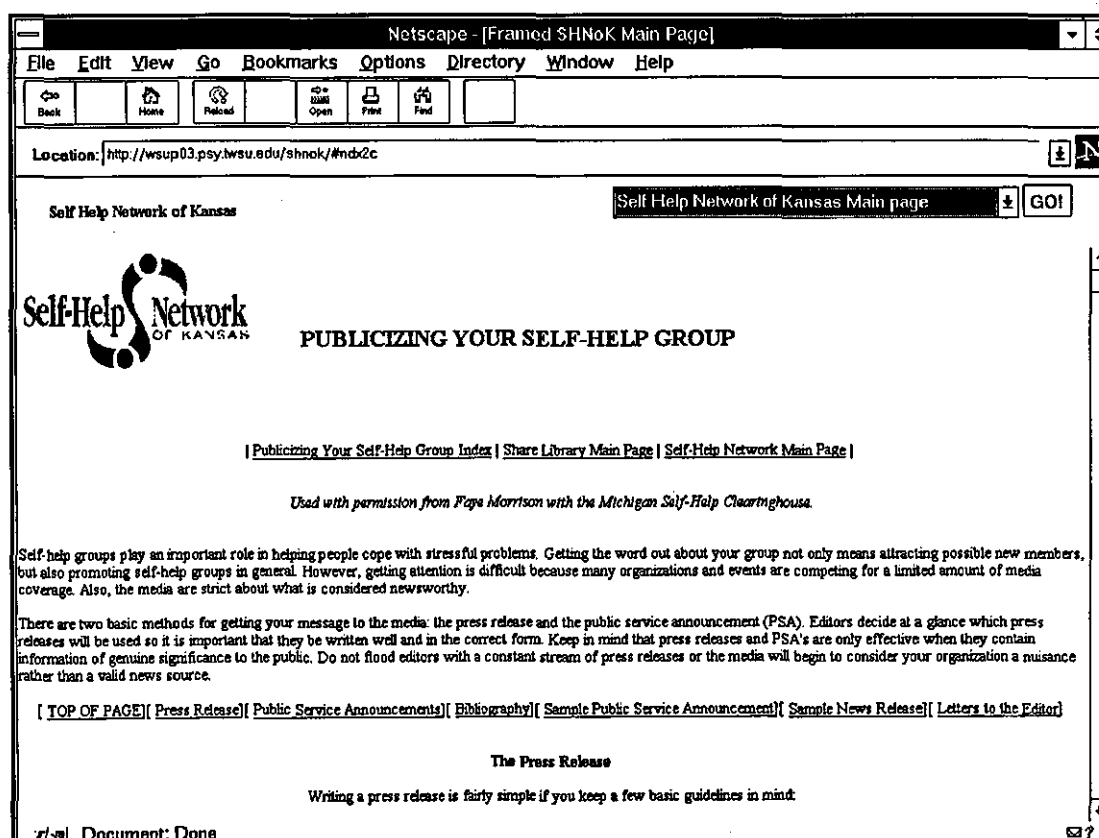


Figure 10.2. Self-Help Network of Kansas: Resources for Groups

The SHARE (Self Help Answer and Exchange Resource) Library contains excellent downloadable articles on a wide range of self help issues, and mirrors the type of resource that the Self Help Nottingham site aims to be. Specific areas covered include group start-up, professional involvement, promotion, self-help group leadership and internal dynamics. For researchers there are brief sections on definitions and a bibliography on group effectiveness, as well as a list of condition-specific research topics covered by the Department of Psychology.

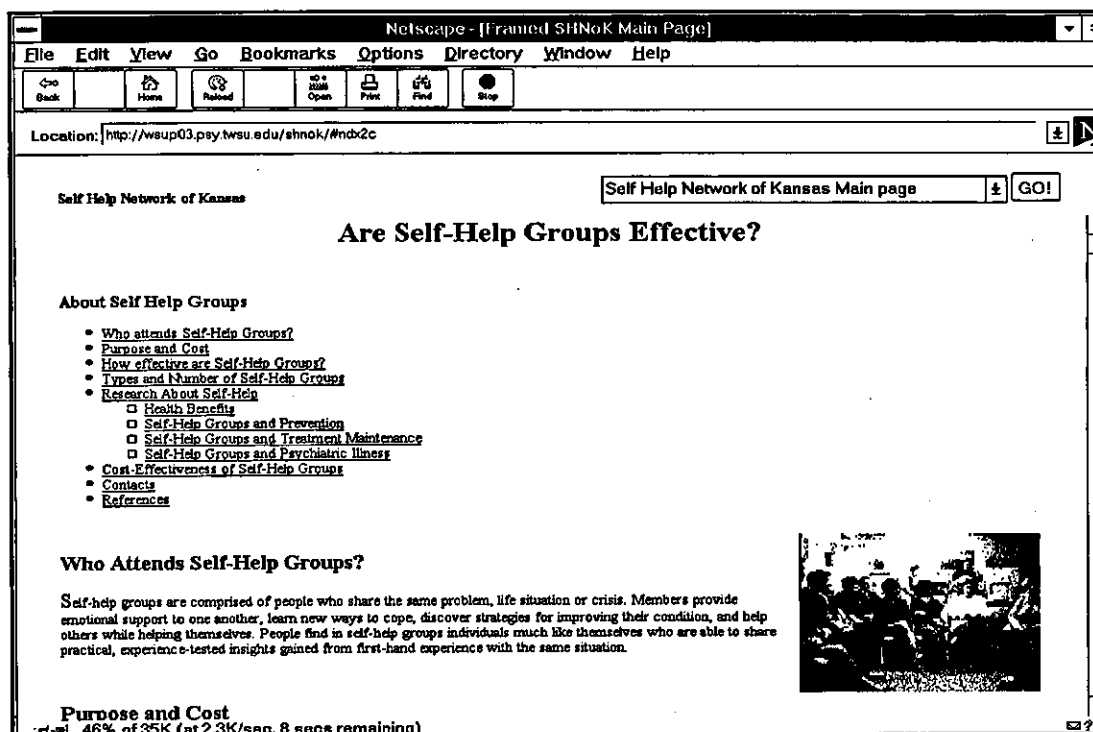


Figure 10.3. Self Help Network of Kansas: Effectiveness of Groups

The site displays the correct balance of content, ease of use and interactivity, backed by the relevancy of its materials to a wide range of potential users.

## 10.2. American Self-Help Clearinghouse<sup>2</sup>

As outlined in Chapter 8, the Self-Help Sourcebook Online represents the logical electronic evolution of Madara's model of the New Jersey Clearinghouse and the searchable database of groups contained on the site uses information provided by the American Self-Help Clearinghouse (as the NJ Clearinghouse is now known.) Details about the site authors are not as clear as they might be (hidden under a FAQ listing when a Contact section would be more appropriate). The parent Mental HealthNet site, founded by Dr. John Grohol (another prominent Internet self-helper) is more psychology- and psychiatry-based, consistent with the US emphasis on these forms of self help.

A clear disclaimer is made concerning content and inclusion:

Self-Help Clearinghouse's listing of a self-help group does not constitute an endorsement of that group. We include groups in the database based upon the report of their organizations being focused upon no-fee mutual aid, i.e., members helping one another.

Functionally the site works well: a WAIS search engine enables precise searching, the results listing national and state groups with brief scope notes, purpose and contact details, affiliations, and e-mail contacts were relevant. "Model groups", an American term which denotes groups which are not official national organisations but which can be contacted for advice on starting a similar group, are also listed and clearly indicated as "model groups" with appropriate disclaimer and advisory notes. The search engine also allows browsing of an alphabetical keyword list. One drawback is the bottom screen menu bar, which is for the parent site and so requires a return to the Sourcebook index page (which requires scrolling down the page each time). A feedback form is included to register new groups, ask questions etc, adding to the site's interactivity.

As well as a brief definition within a list of FAQs, an overview of research and quotes praising self help, the site links to a Mental HealthNet review of research articles<sup>3</sup> which provides brief synopses and bibliographic details from medical literature, subdivided by condition area. Although some details on review inclusion criteria are included (longitudinal and control studies are preferred, as are self-run groups over professional-led) this only goes so far. There is no indication of sources (Medline? Hand-searched journals?) which would be expected by *systematic* review methodology (c.f. Cochrane Collaboration<sup>4</sup>). Nevertheless, a useful introduction for general practioners and clinicians.

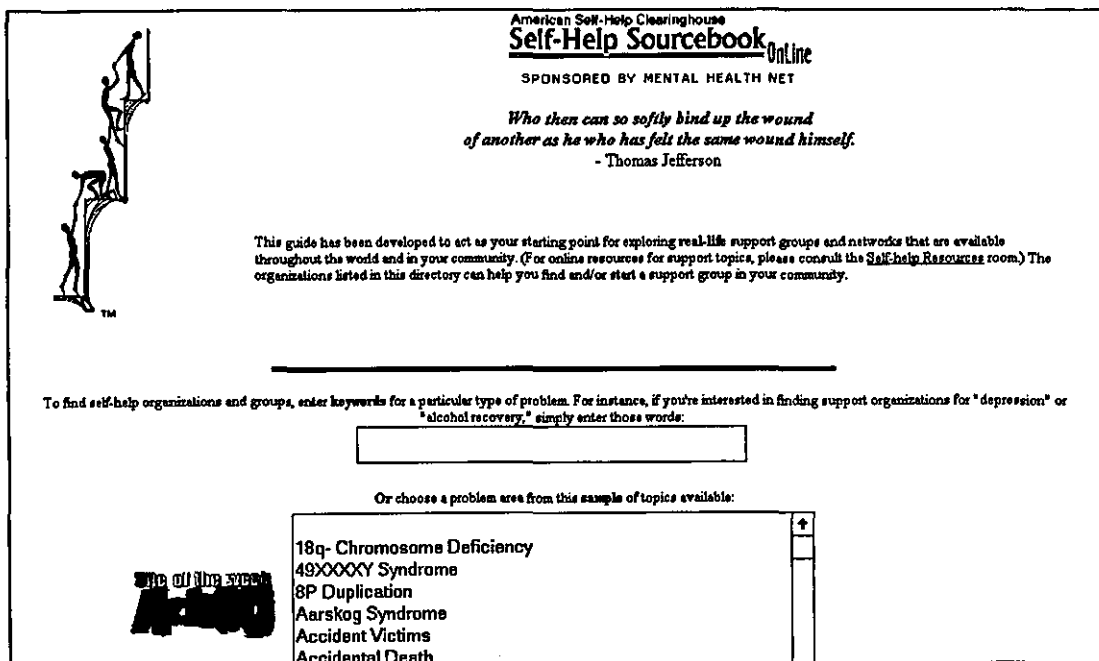



Figure 10.4. Self Help Sourcebook Online: Home Page

Resources targeted at potential self-helpers are briefer in scope than the Kansas material (see above) but focus on similar areas: setting up and running a group, publicity, leadership issues

etc. More importantly, the site includes a guide to setting up an *online* self-help group, the only such guide discovered during the survey. Unfortunately, the emphasis is on "real-time" meetings on commercial services (Compuserve, America Online, Prodigy) which follows from Madara's earlier articles. E-mail discussion lists and BBSs (another US bias) are briefly dealt with and praised for the time they allow for browsing message threads. How relevant this advice is for a UK audience must be judged alongside the US users' familiarity with these commercial services, timing of meetings, difficulties in organisation and publicity, and control.

American Self-Help Clearinghouse  
**Self-Help Sourcebook Online**

mental health 

## STARTING AN ON-LINE SELF-HELP GROUP

We're glad that you are thinking about the possibility of starting a "real time" on-line self-help group. To assist your particular needs, here are a few ideas that will help you get started.

**Table of Contents**

- ☐ [Existing Services](#)
- ☐ [Don't Romanticize](#)
- ☐ [Look and Learn](#)
- ☐ [Taking the Big Step: Planning the Online Conference](#)
- ☐ [Final Thoughts](#)

**Existing Services**

While on-line "real time" meetings occur on commercial services like *CompuServe*, *America Online*, and *Prodigy*, more often live meetings are developing at Internet forum sites, e.g., the *Transformations Forum* (<http://www.transformations.com/>) or *ParentsPlace* (<http://www.parentsplace.com/>). Meetings usually take place at a preset time on a weeknight or weekend. You might want to begin your effort by posting a message in forums on one or more of the national commercial systems. Ask if there are any other individuals interested in learning more about the problem and/or are interested in starting an online group.

Figure 10.5. *Self Help Sourcebook Online: Starting an on-line self help group*

National and International clearinghouse contact details are listed. It is striking that of 67 state and national clearinghouses listed, only 9 have e-mail (13.4%) and 4 maintain websites (6.0%), surprising, perhaps, given the rate at which the Internet has developed in the US. This places Self Help Nottingham's efforts in some perspective. Helpline and toll-free information are listed (by topic) and international clearinghouses (although Self Help Nottingham's listing is out of date).

The *Alphabetical index of Internet resources* on particular health topics<sup>5</sup> is housed at the Mental HealthNet parent site and covers a broad range of health and psychology matters. Once it is entered, however, there are no links back to the Online Sourcebook. Hypertext links and brief descriptions of Web resources are rated by MHN stars and readers' votes (a dubious

review system<sup>6</sup>), and other hypertext-linked headings include newsgroups, e-mail lists (with direct subscription), articles and associations, research and FAQs. As if to prove the Internet's inability to comprehensively index itself, the online support group studied for this dissertation was not listed. All evaluative safeguards must apply when using an unreviewed list of links such as this, and an evaluation service such as OMNI is preferable for an initial search.

### 10.3. Illinois Self-Help Coalition: Support Group Directory Online<sup>7</sup>

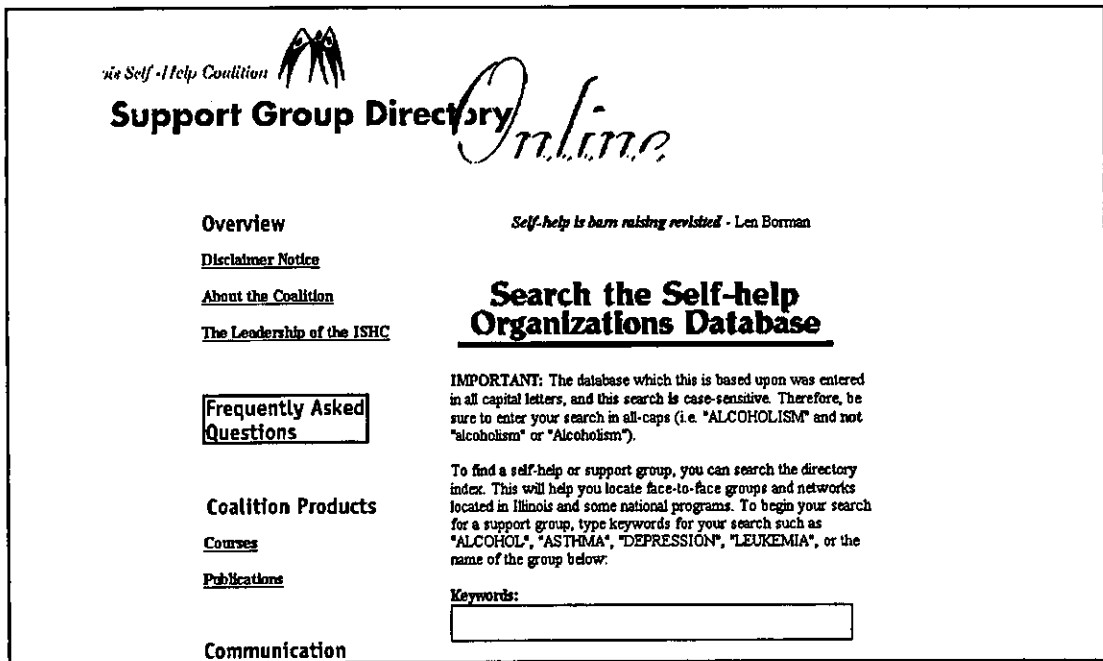


Figure 10.6. Illinois Self-Help Coalition: Home Page

Maintained by Illinois' statewide clearinghouse, the site is notable as the second US example of a searchable directory of support groups. Authoritative and clearly laid out, the site has a clear disclaimer, background on the Coalition and contact details. There are no research or full-text training materials, and the WAIS search engine is far from ideal: it is case-sensitive and requires all capitals, and parsing problems prevent a search with apostrophe, which can be problematic (e.g. Turner's Syndrome, Crohn's Disease). This is not explained, nor is there an alternative browsable index. The database is provided free by a Chicago Internet Service Provider, highlighting the possible difficulties when such work is outsourced to consultancies.

Keyword searches can be qualified by City/Zip Code, a useful local feature. Results are displayed in boxes with contact details, scope and purpose, meeting times etc. Personal names appear to be suppressed, but contact telephone numbers are given.

#### 10.4. Other US and Canadian Clearinghouses

More basic, entry-level sites include those for Champaign County<sup>8</sup>, Nova Scotia<sup>9</sup> and El Paso<sup>10</sup>. These contain contact details, definitions, lists of services local addresses and lists of publications and training materials, but for the most part do not include full-text materials. They represent a similar level of information content and site interactivity as the existing Self Help Nottingham site.

#### 10.5. Support-Group.com<sup>11</sup>

A collection of resources geared around health, personal and relationship issues, Support-Group.com is a private venture which owned and operated by Annette and Archie Hensley of Melbourne, Florida. No further information on the authors is provided. Commercial banner advertising is prominent, mixed with public service organisations. Clear disclaimers are included relating to content, the need to consult a clinical professional etc.

**DISCLAIMER**

This web site provides general information: Do not use the information on these pages as a substitute for evaluation and treatment by a Professional Health Care Provider. You are expected to read the full disclaimer and further access to this site is under the condition that you agree to abide by its terms and conditions.

Support-Group.com

...Bulletin Boards, Online Support Groups, Internet Resources, and More!

- A -

- Aarskog Syndrome
- Adoption
- Advocacy Issues
- Aging
- AIDS/HIV
- Allergy
- Alopecia / Hair Loss
- Alpha 1 - Antitrypsin Deficiency (AIAD)
- Alzheimer's Disease
- Amputation
- Amiotropic Lateral Sclerosis (ALS)
- Anemia
  - Aplastic Anemia
  - Fanconi's Anemia
- Anger Management
- Anxiety / Panic Disorders
- Aplastic Anemia
- Anorexia Nervosa (Eating Disorders)

- B -

- Batten Disease
- Bell's Palsy
- Bereavement
- Binge Eating (Eating Disorders)
- Bipolar Disorder
- Bipolar Chat
- Bipolar Significant Others (BPSO)
- Bipolar Teens
- Birth Control (Family Planning)
- Blindness (Visual Impairment)
- Borderline Personality Disorder (BPD)
- Breast Cancer
- Bronchitis
- Bulimia (Eating Disorders)
- Burns

Figure 10.7. Support-group.com: Index



The site serves as a valuable collection of 175 bulletin boards on specific conditions or topics, links to Internet Relay Chat rooms or “channels” (the latest phase of American self-help discussion revolves increasingly around the promotion of these real-time services) as well as providing guidelines for Online Chat Group Facilitators. These utilise the bulletin boards to set meeting times, and attendance is recorded and send to Support-Group.com.

Internet resources are indexed in alphabetical tables by subject area, and then subdivided into local & state support groups (incomprehensive, being based on voluntary submission of details), national & international organisations, general information and pamphlet material, professional resources, USENET groups and discussion lists, medications etc. Not every topic is so fully subdivided, with the result that coverage is inconsistent and all-too-brief in many areas.

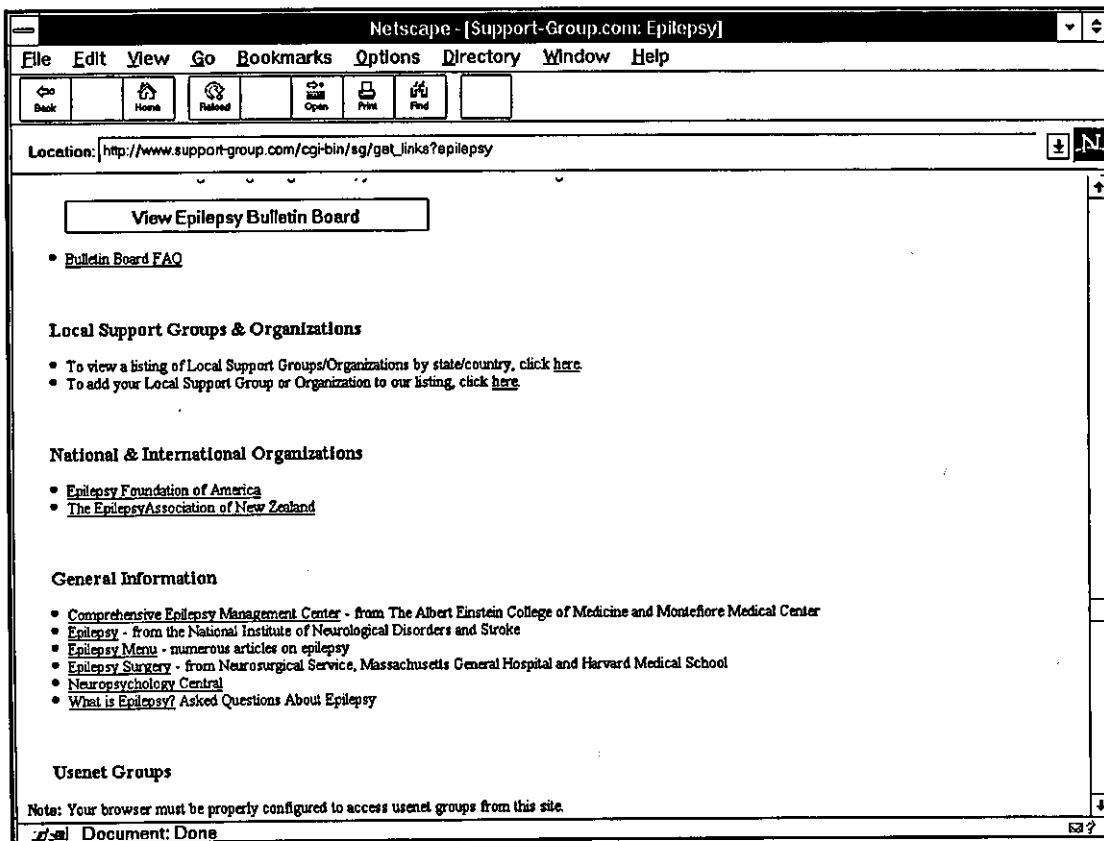



Figure 10.8. Support-group.com: types of resource

## 10.6. Other Resources

Following results from general searches or links through specific sites is a less effective way of obtaining specific materials, but it is possible to find relevant, authoritative and well-

referenced report material. The Child & Family Canada report is a case in point<sup>12</sup>, since it is "grey literature" and unlikely to be retrieved through Internet or traditional Medline searches.



Home Page   Search   What's New!   Site Map   Feedback   Organizations

## Self-Help and Support Groups for Parents of Children with Special Needs in Canada

### A Background Report

by Janice MacAulay

This project was funded by the Child Mental Health Unit of Health Canada and undertaken by the Canadian Association of Family Resource Programs in 1994 - 1995. Maureen Kellerman directed the project and Janice MacAulay was the researcher and writer.

**Purpose:**

- to obtain a preliminary idea of the extent of involvement in self-help and support groups by parents of children with special needs in Canada;
- to discover the kinds of supports that are currently provided to such groups;
- to examine the role of professionals vis à vis self-help and support groups;
- to determine issues related to the functioning of self-help/support groups; and
- to identify mechanisms that would support the continued development of parent mutual aid activities.

Figure Example of full-text self help report material

Such material requires the fullest of critical evaluation methods, as it is often "free-standing" or its connection to an author or publishing body is tenuous. The journalistic material covered in the literature review falls into this category: it may be the most accessible for Internet newcomers, for reasons of style and the contrivances of commercial search engines, but it is also the most susceptible to disappearing links and references are thin on the ground.

<sup>1</sup> Self Help Network of Kansas. *Home page*. (URL: <http://wsup03.psy.twsu.edu/shnok/>), 2 September 1997.

<sup>2</sup> American Self-Help Clearinghouse. *Self-help sourcebook online*. (URL: <http://www.cmhc.com/selfhelp/>), 16 July 1997.

<sup>3</sup> Kyrouz, Elaina M. & Keith Humphreys. *A review of research on the effectiveness of self-help mutual aid groups*. (URL: <http://www.cmhc.com/articles/selfres.htm>), 11 September 1997.

<sup>4</sup> UK Cochrane Centre. *About the Cochrane Library*. (URL: <http://www.cochrane.co.uk/aboutpag.htm>), 10 September 1997.

<sup>5</sup> Mental Health Net. *Disorders and treatments*. (URL: <http://www.cmhc.com/selfhelp.htm>), 11 September 1997.

<sup>6</sup> McNab, Alison et al. Never mind the quality, check the badge-width. *Ariadne*, 1997, 9, 6-7.

<sup>7</sup> Illinois Self-Help Coalition. *Support group directory online*. (URL: <http://www.selfhelp-illinois.org/>), 2 September 1997.

- <sup>8</sup> **Champaign County Self Help Center.** *Home page.* (URL: <http://www.prairienet.org/community/health/selfhelp/>), 2 September 1997.
- <sup>9</sup> **Self-Help Connection [Nova Scotia].** (URL: <http://cfn.cs.dal.ca/CommunitySupport/SHC/index.html>), 16 July 1997.
- <sup>10</sup> **El Paso Area Self-help Support Groups.** *Home page.* (URL: <http://rgfn.epcc.edu/users/as796/>), 2 September 1997.
- <sup>11</sup> **Support Group.com.** *Index pages.* (URL: <http://www.support-group.com/index.htm>), 2 September 1997.
- <sup>12</sup> **MacAulay, Janice.** *Self-Help and Support Groups for Parents of Children with Special Needs in Canada: A Background Report.* (URL: <http://www.cfc-efc.ca/docs/00000444.htm>), 2 September 1997.

## **Chapter 11: World Wide Web Resource Site: Design & Implementation**

### **11.1. Overall Aims**

This WWW resource is viewed as an opportunity to develop a working model that brings together the various elements of organisational objectives, information-seeking behaviour, strategic marketing and the implementation of IT in the voluntary sector, synthesising the findings of my research within a framework of current best practice that can be further developed by Self Help Nottingham.

A guiding principle was that the site should be relevant to the organisation's internal and external functions, utilising textual and intellectual content from the group where practicable, and building on their current knowledge base. The site should not represent the triumph of style over content, but a natural extension of Self Help Nottingham's support activity and its wider ambitions. In short, a realistic and concrete embodiment of the whole research project and its various themes.

### **11.2. Background**

Self Help Nottingham's web presence pre-dates this project, but the existing provision is markedly limited in scope and maintained as part of the regional Emnet collaboration, which indexes it alongside local charitable organisations several stages from the parent site welcome page. From the outset there are difficulties in the location or profile of the site in terms of its visibility to health and social care professionals, public information specialists and other potential users. With this in mind, the group committed itself to registering its own domain name and obtaining an e-mail account with GlobalNet, affirming the need to maintain responsibility for the site "in-house". The information officer indicated the importance of "keeping it in our own hands", control being vital since Emnet's long-term funding was far from secure. This is reinforced by the experience at the National Institute for Social Work, as documented by Watson:

our concern with [outsourcing] is that the Internet will not be seen as integral to the organisation's use of information and as such will be poorly maintained and promoted<sup>1</sup>.

The Emnet-hosted site that contains the group's existing web pages<sup>2</sup> represents a basic entry-level site which is minimally interactive and duplicates for the most part the printed introduction to the SHN annual directory of self help groups. The site comprised

- Home page/Contact details
- Brief definition of Self Help
- Listing of subject areas/conditions covered by groups
- Brief publications list
- New home appeal
- UK contact details

with a simple hypertext menu bar linking pages. The group recognised its limitations, but resources and lack of expertise prevented its further development. However static the site, it nevertheless indicates that for the size of organisation the commitment and awareness of Internet issues was quite advanced, fuelled in no small part by the information officer's interest and access to the Internet at home. This IT familiarity will be integral to the group's long-term strategy and internal training programmes.

### 11.3. Marketing Issues

The site represents the opportunity to take advantage of the lower communication costs, international information distribution and increased visibility afforded by the Internet<sup>3 4</sup>. "Value-added" elements are derived from the quality of material available (e.g full-text resources) and the functionality of the site: content and design must reinforce each other.

Can an audience for the site be defined? The site identifies General Practitioners and other primary care professionals, new and existing self help groups, and individuals searching for a group as key targets, with more general resources aimed at researchers, policy-makers and community development workers.

### 11.4. Technical Aspects

Simplicity and flexibility of site architecture would allow the group to build on the model and assert their ownership of its content.

The use of Netscape Gold 3.01's integrated WYSIWYG editor (utilising HTML 3.2) represents a compromise between the researcher's only recent HTML familiarity, ease of use, time available and browser compatibility. Any Netscape-specific features were minimised to

ensure the Web resource could be equally accessible by earlier browsers of any type, and the site was tested on earlier versions of Netscape and Internet Explorer. It is vital to remember the low-level capability of the systems of many potential users, and to target the site accordingly<sup>5</sup>. No assumptions are made regarding the currency of browsers. The site aims at *inclusivity*, otherwise the arguments outlined above on social exclusion and breadth of access will not be met.

Each page is based on a standard template. A single two-column table was used to enable the use of a button menu bar on the left of each page to ensure consistent ease of navigation, with formatted content on the right. Each page carries a specific <TITLE> tag, and the Home Page contains <META> tags to include a range of subject keywords across the health and social care sector. Care is taken to include plurals and hyphen versions (*self help*, *self-help*, etc.) to widen the scope available to search engines for indexing purposes.

Eventually, it may be possible to develop a frame to contain the button menu and to offer two sites (for frame-enabled and non-frame-enabled browsers) split from a central "welcome" page.

### 11.5. Graphic content

Graphics were used only as an aid to site navigation or for a specific purpose (e.g the provision of a map, sponsor logos etc.) A balance is struck between clarity of design, utility and visual impression. The site aims at looking professional (it is hoped it will be accessed by GPs, clinicians and policy-makers, among others) and reflecting the group's intention to raise their profile as a "centre of excellence."

Original GIF graphics were composed for each button, using only grey, black and white colouring for clarity against a blue margin, to ensure access by those with limited colour monitor capabilities. The SHN logo was included at the head of each page to reinforce branding/identity. Since HTTP protocol needs to reestablish connection for each image, excessive use of images was avoided. <ALT> tags were included for all images to ensure text-only browsers such as Lynx were not excluded, nor those users whose browsers are set to ignore images on loading. In addition, a hypertext menu bar is included at the foot of each page (since, without frames, scrolling is required for some pages), and extensive use made of links between pages within the actual text to encourage interactivity.

## 11.6. File Structure

Three directories were created to contain:

- HTML files (the main pages)
- Button Menu GIFs
- Other GIFs (sponsors, maps etc.)

As the site is initially small-scale, any changes will be suitably served by this file structure, but significant expansion or introduction of forms, a listserv forum or frames would necessitate significant restructuring.

## 11.7. Site Architecture

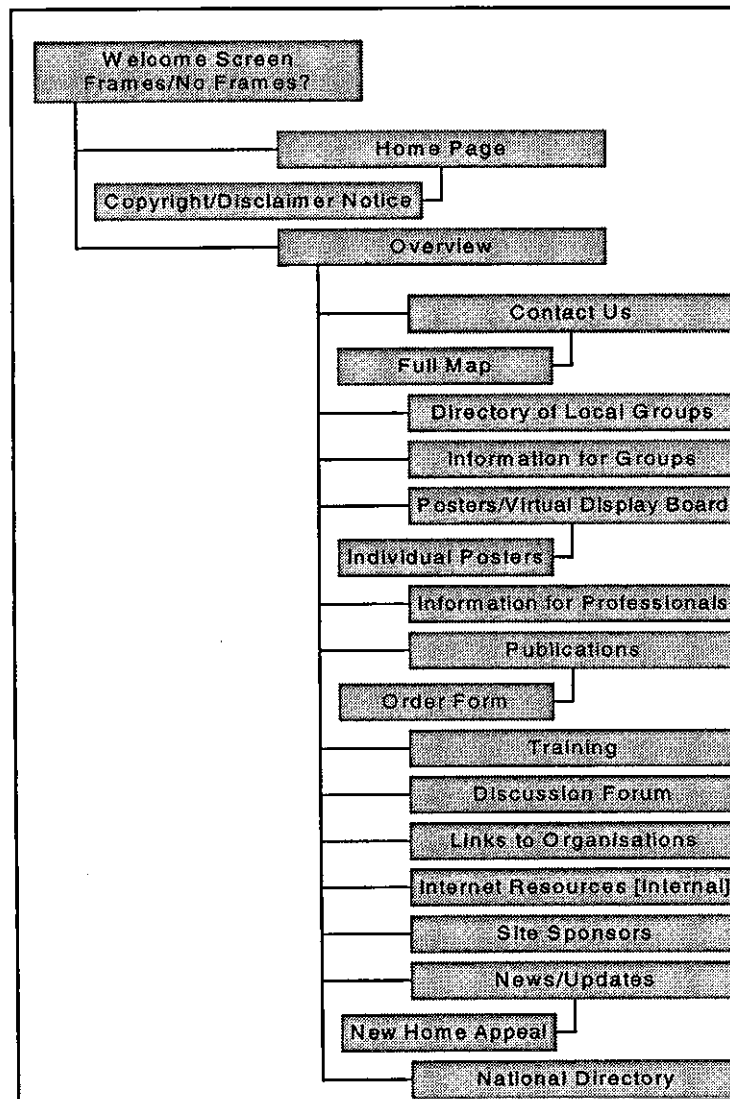


Figure 11.1. Web Resource Architecture [overview]

## **11.8. Site Content**

### **11.8.1. Home Page**

As a mission statement, this page clarifies the organisation's work and underlines their "re-launch" as Self Help Nottingham (many sites still list them under their previous name). It emphasises the aims both of the organisation and of the Web resource site, as well as stating ownership and responsibility, currency of updates, and links to the Copyright Statement/Disclaimer. It aims to set the tone for the site as a whole: professional, high in content, focused and well structured.

### **11.8.2. Overview**

The equivalent of a Table of Contents, the Overview gives a fuller indication of what each section contains and encourages users to explore the site, safe in the knowledge that they can return to this textual site map if the menu bar proves insufficient.

### **11.8.3. Contact Us**

Address and telephone details, an e-mail "mail-to" link and "how to find us" map are included. The map is scaled down and links to a full-page map which can be printed out. The image was scanned from an existing publicity leaflet and minimised as a GIF, without compromising clarity of image. The Contact Us page is linked to throughout the site, to reinforce the centrality of the group as a real, contactable resource with resources "on the ground".

### **11.8.4. Directory**

An undeveloped part of the site, but one which might in future contain a searchable database of the Directory of Self Help and Carers' Groups, open or password-protected as part of an intranet. See evaluation of the NAGD online directory and other case studies in Chapter 9.



### **11.8.5. Groups**

Emphasises the local context, with a link to the potential directory, but also establishes Self Help Nottingham as a source for UK information through their Connect Self Help UK directory (see below). This national aspect will be strengthened as their profile develops and is reinforced by the content of the site, the discussion forum etc. The group regularly fields calls from outside the county, with the telephone number obtained in many cases from the Emnet site.

This page also contains excerpts from one of the team's publications for new groups, reformatted for the site, to serve as an example of the sort of full-text materials that could be offered to groups and individuals. This may be restricted in some way or made part of a subscription / "Friends of Self Help Nottingham" service to provide updates to training materials, or to pilot new publications to specific groups.

### **11.8.6. Posters**

Following on from the Groups page, the virtual noticeboard utilises existing poster material to broadcast the work of individual groups. This could be done as part of an intranet based around local/regional NHS networks, or more openly, with the personal contact details/venue information removed so that calls were dealt by Self Help Nottingham centrally (so protecting group leaders). Although basic in design, this aspect of the site could be greatly developed with a view to becoming a key source in public libraries, community centres, GP surgeries and outpatients clinics. Posters can be printed as single sheets of A4 for display in these locations, reinforcing the publicity work already carried out by SHN.

If linked with an online Directory, this offers the potential for widespread dissemination of information about groups to the local community: the directory could be searched by condition and location, scope notes, contact details and meeting times obtained, and a poster printed out for display.

### **11.8.7. Professionals**

Primary care professionals are targeted (for the reasons outlined in earlier defining chapters on self help) because they play a key role in referral to groups and in many cases as a group-

sanctioned information resource. This full-text source, based on a pamphlet developed by SHN and the FHSA, addresses issues of concern to GPs and promotes self help approaches. It contains hypertext links to specific sections from a top menu bar, and can be downloaded by Gps. This is the type of material that could encourage GP websites to include the SHN site in resource directories, lists of links etc. and establish a reputation for focused full-text sources.

#### **11.8.8. Publications**

Both the *Starting Off* and GP full-text resources link to the central Publications list, which gives full bibliographic, price details and reviews where possible, as well as linking to an order form which can be printed. In the future, an online order form could be developed. Orders for publications have already been received from Australia, underlining the international nature of such transactions. Care must be taken when stating prices, postage & packing etc., since currency conversion is now an issue.

#### **11.8.9. Training**

Lists training courses run by the team and provides details of venue, dates, guide to content etc.

#### **11.8.10. Forum**

The opportunity exists to develop a discussion list linked to the site, so reinforcing the identity of Self help Nottingham as a key national resource in self help research and forging international links. The change of name and the team's previous history make such a re-launch doubly important (several sites visited were found to contain contact details under the former title). The NISW site evaluated earlier runs two social work-related listservs, hosted by their Internet Service provider: such work reinforces NISW's association with practice and policy matters, provides overseas contacts etc. [see recommendation below]

#### **11.8.11. Organisations**

Reciprocal links to organisations already in partnership with Self Help Nottingham. These should be evaluated internally and monitored. Limited at present. Reciprocal links should be confirmed by e-mail to cover copyright issues.

### 11.8.12. Resources

This section addresses a wide range of issues: training and familiarity with Internet sources, research and evaluation tools, models and examples of best practice, site maintenance and legal issues. It represents that two levels of Internet use: SHN utilising the Internet both to *obtain* information and to *disseminate* information and establish a national profile. It is included on the site model, but is intended for *internal* use: initially the site must not make the mistake made by many organisations in simply providing lists of links which take users away from the site, so compromising the profile-building and branding opportunities. It is not SHN's purpose to provide a gateway to voluntary sector resources: specialist academic and research sites will do that. Eventually, using the research tools included, bookmarks might be developed for self help resources which might warrant a Links section.

The Resources section is the filtered, structured assembly of the evaluative and site design work of this dissertation, a long-term practical information resource that addresses the needs to develop expertise and encourage training. It aims at providing a desktop portfolio of tools, set out in such a way as to demonstrate the types of research resources available and to provide a "starter-kit" for the sort of issues in early implementation of the site (hence the links to the Data Protection Registrar<sup>6</sup>, collections on legal issues<sup>7 8</sup>, HTML validation software<sup>9 10</sup>, NETSKILLS training materials<sup>11</sup>, style guides<sup>12</sup> etc.)

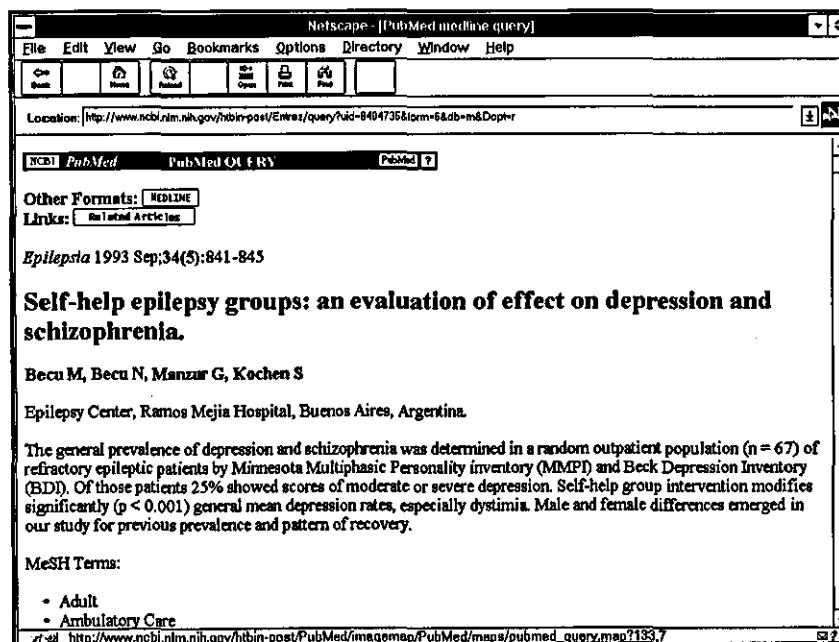


Figure 11.2. Sample NLM PubMed Search: Results Display

Research on specific health issues is not strictly a priority for SHN, since such enquiries are forwarded to Trent Healthline. However, the information function of a potential UK centre of excellence/clearinghouse could profit from medical research databases such as the US National Library of Medicine's *PubMed* system. Although complex MESH searching is inappropriate initially, the currency and authority of the materials provides the foundation for developing current awareness services to specific groups, or extending SHN's research into the professional interface with groups. Such efforts are likely to be restricted by limited time and expertise, but would contribute to the researchers network envisaged by SHN as well as providing subject-focused bibliographies/abstracts which could be mounted on the site.

OMNI<sup>13</sup> and SOSIG<sup>14</sup> offer authoritative, well-resourced evaluative subject gateways to resources, with simple or advanced WAIS search engines and training documentation. OMNI provides more results on self-help groups in health and psychology, but SOSIG may eventually develop more social work/social welfare links. Compared with the unevaluated links provided by PsychWeb<sup>15</sup>, with its US mental health emphasis, the value of evaluated gateways is immediately apparent. The NHS Confederation gateway<sup>16</sup> offers links to health-related sites by topic area, and could provide contact points for Primary Care and NHS Trust sites as the NHS network is expanded.

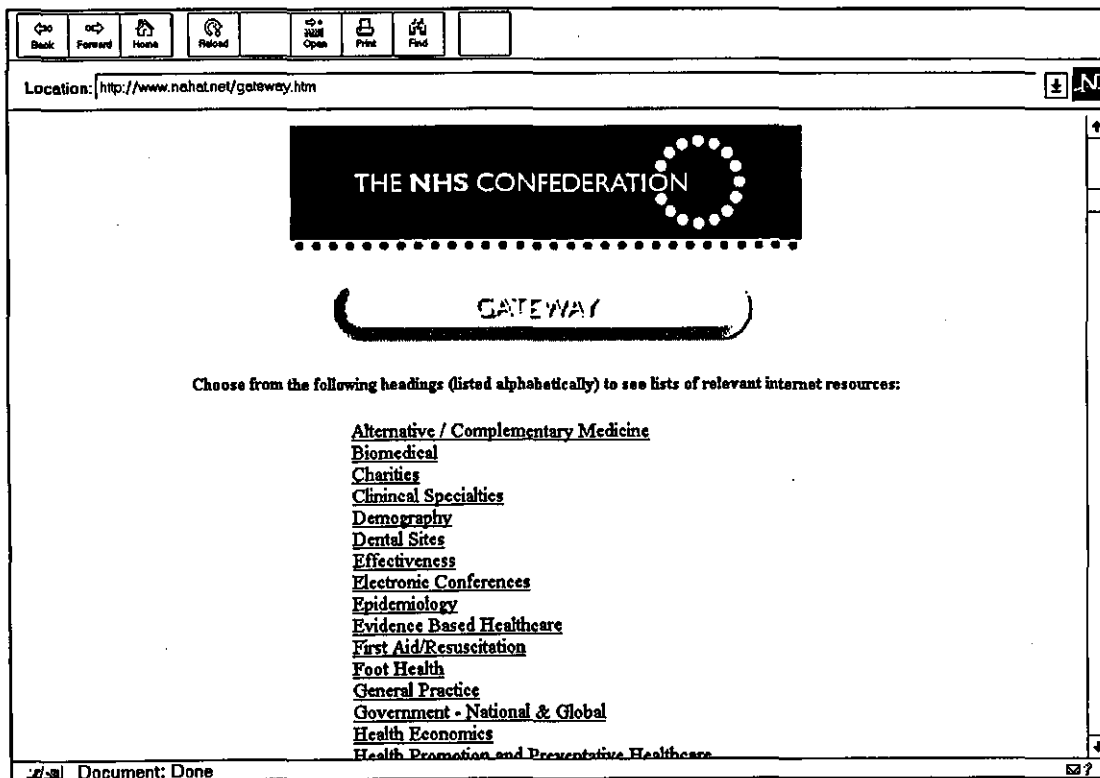


Figure 11.3. NHS Confederation Gateway

In addition to those sites already covered in the case studies chapter, UK voluntary sector sites provide useful comparisons and give an overall impression of the current state of play. The Mental Health Foundation<sup>17</sup> provides downloadable pamphlets, briefings and press releases, as well as a basic contacts directory. The *Community Care*<sup>18</sup> site gives no information on the authors (despite their claim to uphold the Health on the Net Code), and hosts charity pages, provides an index of Internet health links, the UK ME Web, and links to UK charity sites. The Charities Aid Foundation *CharityNet*<sup>19</sup> site requires “free” registration before accessing services, but given Self Help Nottingham’s new independent charitable status will prove a valuable central information source, as will the National Lottery Charities Board site<sup>20</sup>. The *UK Fundraising*<sup>21</sup> site groups together reviews and examples of using the Internet to raise funds, which is beyond SHN’s scope at present but may develop as part of the “new home” appeal. The site should be utilised with caution, however, since it prominently advertises its author’s publication and covers larger, more “corporate” charities (Greenpeace, Comic Relief etc.), limiting its relevancy and validity in this context.

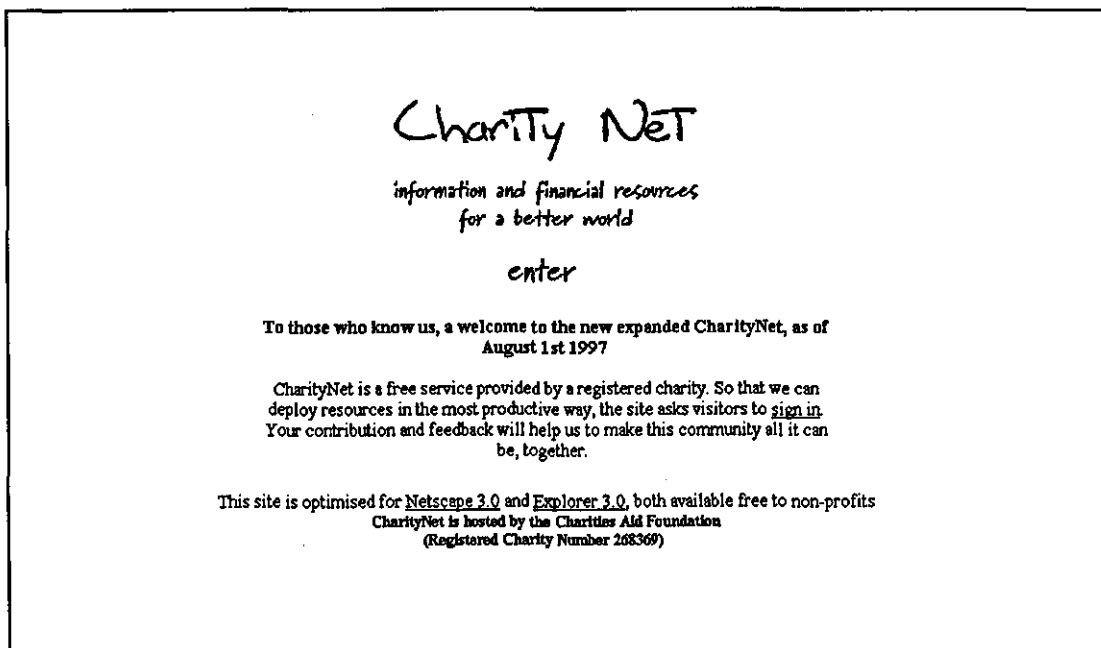


Figure 11.4. Charities Aid Foundation's "CharityNet"

Additional sections include search tools for USENET groups and discussion lists<sup>22 23 24</sup>, Online Communities resource sites<sup>25</sup>, the Government Information Service<sup>26</sup> (for links to local authorities, Departments of Health, Social Security etc.) and publishers specialising in self help materials<sup>27</sup>.

### 11.8.13. Site Sponsors

The annual directory of groups is already sponsored by health and commercial organisations, so the inclusion of site sponsors is a logical next step, and may provide valuable resources to cover the cost of running a listserv or maintaining the site generally. The logos are greyscaled and converted to GIFs, with optional hypertext links to the sponsors' sites.

### 11.8.14. News

As the NISW site has shown, it is increasingly content that defines site quality in the voluntary sector, and the News section contains the re-formatted text of the group's newsletter and a link to the "new home" appeal. The newsletter can now be disseminated beyond the traditional internal health and community links, and so serves the target audiences of group members, supporters and professionals.

### 11.8.15. National Directory

Self Help Nottingham have produced *Connect Self Help UK*, a national directory of voluntary sector development agencies offering support to people setting up or working with self help groups. This is given a separate web page, since it is a unique publication and serves as a focal point for the team's national information role. This aspect of the site reinforces the wider issues of forging a national profile for self help, avoiding duplication of effort, and branding Self Help Nottingham publications as *de facto* standards in the field.

## 11.9. Full-text sources: costs and benefits

Some concern has been raised by the organisation over the free availability of material previously sold in printed form (and thus a significant source of revenue). It may be that some new publications are made available in an "electronic only" format or that updates are handled in this format. There is, however, some strength in Watson's argument that "loss of income through lost sales of the printed version appears to be more than offset by the positive feedback,"<sup>28</sup> particularly for low-cost pamphlets with negligible profit margins. To be seen as an innovator at a time of low activity in the sector may yield long-term benefits (workshops, training opportunities, a raised profile, specific funding applications) that are difficult to quantify at this stage. Consider the time taken to answer routine enquiries: a Frequently

Asked Questions list may answer these points and ease the pressure on telephone enquiry services. Or the administrative effort in calculating currency conversion for foreign orders, postage etc., all for a £1.50 pamphlet.

### **11.10. Legal and Ethical Issues**

Since at this initial stage only Self Help Nottingham core staff are likely to add to the resource, lengthy acceptable use policies can be postponed. However, if individual groups are later encouraged to develop their own pages, channelled through SHN, legal responsibility for content might still rest with Self Help Nottingham unless strong acceptable use guidelines are in place. The legal context is still far from clear, but certain fundamental issues must be considered.

A copyright disclaimer is included as a link from the Home Page to satisfy the requirement that

Organisations which make information available on the Internet for which they have copyright should explicitly state their copyright ownership by including an appropriate notice within the body of information<sup>29</sup>.

Accuracy of information is vital, in legal and quality terms. Without a suitably prominent and unequivocal disclaimer, the group could be liable for damages where information is read and relied upon and loss is suffered<sup>30</sup>.

Links to other sites are similarly limited initially, but if expanded must involve a routine check to ensure no libellous or other offensive material is included on a linked site, since this could result in SHN being liable<sup>31</sup>. It is difficult, if not impossible, to avoid other organisations linking to the site, but this will for the most part be advantageous, and a routine search engine sweep for links should enable such sites to be monitored and corrective action taken against individual site administrators.

#### **11.10.1. Specific Legislation**

The site may not contain, or be used to distribute, or have direct links to, material which breaches, or is likely to likely to breach:

- The Obscene Publications Act 1959
- The Sex Discrimination Act 1975
- The Race Relations Act 1976
- The Protection of Children Act 1978
- The Contempt of Court Act 1981
- The Data Protection Act 1984
- The Telecommunications Act 1984
- The Public Order Act 1986
- The Copyright, Designs and Patents Act 1988
- The Computer Misuse Act 1990
- The Trademarks Act 1994

Of particular relevance to SHN at this stage are the copyright permission required to use site sponsor logos (this has been granted for the printed directory but will need additional permission for the site) and the Data Protection implications of an online directory of groups or other information published about individuals. Since SHN already complies with the Act for its database activity this will involve minor changes.

### 11.11. Evaluation

In addition to preparatory meetings, a formal presentation/discussion and an ongoing dialogue regarding site content, a final evaluation of the site was conducted with the information officer. Using a semi-structured interview technique based around the user negotiating each aspect of the web resource, it was possible to draw general conclusions about the way the site might fit with the other information services. Many of these have been incorporated in the above discussion of specific pages since the actual site represents close collaboration with the group throughout the design process.

Overall, the fully functional site model was viewed as an “added bonus” in light of the arrival of the group’s Internet connection ahead of schedule, one that has significantly advanced their agenda and raised many issues which will have to be addressed if the site is to be developed further. Staffing and resourcing issues cannot be avoided: a web site cannot make up for a lack of human resources at ground level, no matter how content-driven its design. The organisation still views the Internet as “another networking resource” and an opportunity to “keep up with developments<sup>32</sup>”. This fits with the view that voluntary organisations will somehow be left behind if they refuse to tackle IT head-on and also demonstrates that *strategic* use remains ill-defined at this stage.



## 11.12. Recommendations

An Internet *presence* is not sufficient; *presence* implies a certain passivity, when what is required is a dynamic and interactive *engagement* with this new medium. The long-term integrity of the site rests with the organisation. As with all forms of change, this is both an opportunity and a challenge to existing resources and practices.

The site *itself* represents an overall recommendation, so closely are its findings enmeshed with the practical application of site design to project requirements. The site was originally conceived as a working model, but extended beyond that to a concrete resource, open to adaptation but constructed in response to a set of organisational and research-based issues

Site promotion: the Submit-it<sup>33</sup> site enables URL's to be sent to leading search engines such as Alta Vista and Infoseek, thus speeding up the process by which the site is indexed. Full details on the subject coverage of the site should be given, in addition to those <META> tagges keywords detailed earlier.

Discussion Lists (e.g. SLFHLP, CUSSNET, GP-UK) can be utilised (after free subscription) to publicise the launch of the site, as can individual press releases/URL submission to gateways such as SOSIG, Nahat, OMNI, and the individual sites evaluated earlier.

Traditional in-house networks for publicity and media (community development and NHS-based) as well as informal contacts, research links, affiliations etc. should be incorporated.

Examine the use of the PubMed Medline database to generate bibliographic materials and research profiles on self help for specific conditions, which can then be mounted as a resource on the site and/or used locally by groups.

Develop familiarity with the internal Resources page and incorporate it in training programmes for SHN staff, using it as a means of monitoring IT activity in the voluntary sector.

Develop Frequently Asked Questions-style resources around definitions of self help activity or other material that is regularly requested by other means.

Formulate a clear policy on who decides on content.

Utilise *PubMed* to update the bibliography on professional involvement with groups, and run

Explore the possibility of GlobalNet hosting a listserv-based discussion list with Self Help Nottingham as list moderators. Given that the few self help-specific discussion lists are dominated by American practitioners, with all that implies for the UK-specific welfare context, such a forum for UK policy matters is vital. Self Help Nottingham have already indicated an intention to develop their resources and serve as a "central deposit" for self help research materials, as well as establishing a network of self help researchers. The listserv is a logical means of giving such ambitions a practical communications framework.

Explore further the potential of an interactive publications order form or more defined feedback form, and the practicalities of the GlobalNet server providing subscription-based password-protected Membership areas.

Pursue links with the NAGD and Tagish to examine the practicalities of mounting the directory of groups online.

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<sup>1</sup> **Watson, Mark.** Why should you be on the Net? *Library Association Record*, 1996, **98** (11), 579.

<sup>2</sup> **Self Help Nottingham.** *Home page.* (URL: <http://www.emnet.co.uk/SelfHelp/>), 8 September 1997.

<sup>3</sup> **Sterne, Jim.** *World Wide Web marketing: integrating the Internet into your marketing strategy.* New York: John Wiley, 1995, xv-xvi.

<sup>4</sup> **Ellsworth, Jill H. & Matthew V. Ellsworth.** *Marketing on the Internet: multimedia strategies for the World Wide Web.* New York: John Wiley, 1995.

<sup>5</sup> **Snyder, Joel.** Good, bad and ugly web pages. *Internet World*, 1996, April, 26-27.

<sup>6</sup> **Data Protection Registrar.** *Home page.* (URL: <http://www.open.gov.uk/dpr/dprhome.htm>), 2 September 1997.

<sup>7</sup> **Copyright Licensing Agency.** *Home page.* (URL: <http://www.CLA.co.uk/>), 2 September 1997.

<sup>8</sup> **Barrow, Edward.** *Edward Barrow's Unofficial Internet Copyright Pages.* (URL: <http://www.plato32.demon.co.uk/Edward/>), 10 September 1997.

<sup>9</sup> **Bobby.** *Home page. [HTML validation service].* (URL: <http://www.cast.org/bobby>), 10 September 1997.

<sup>10</sup> **WebTechs.** *HTML validation software.* (URL: <http://www.hensa.ac.uk/html-val-svc>), 10 September 1997.

<sup>11</sup> **Netskills.** (URL: <http://www.netskills.ac.uk/>), 2 September 1997.

<sup>12</sup> **Yale C/AIM Style Guide.** *Mirror site.* (URL: <http://hosted.ukoln.ac.uk/mirrored/web-authoring/caim/caim/>), 10 September 1997.

<sup>13</sup> **OMNI.** *Home page.* (URL: <http://omni.ac.uk/>), 2 September 1997.

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- <sup>14</sup> **SOSIG.** *Social Science Information Gateway.* (URL: <http://sosig.esrc.bris.ac.uk/>), 2 September 1997.
- <sup>15</sup> **PsychWeb.** *Psychology self-help resources on the Internet.* (URL: <http://www.gasou.edu/psychweb/resource/selfhelp.htm>), 2 September 1997.
- <sup>16</sup> **NHS Confederation.** *Gateway.* (URL: <http://www.nahat.net/gateway.htm>), 2 September 1997.
- <sup>17</sup> **Mental Health Foundation.** *Sources of help.* (URL: <http://www.mentalhealth.org.uk/helplist.htm>), 2 September 1997.
- <sup>18</sup> **Community-Care.** *Home page.* (URL: <http://www.community-care.org.uk/>), 2 September 1997.
- <sup>19</sup> **Charities Aid Foundation.** *CharityNet Home page.* (URL: <http://www.charitynet.org/>), 10 September 1997.
- <sup>20</sup> **National Lottery Charities Board.** *Home page.* (URL: <http://www.nlcb.org.uk/>), 2 September 1997.
- <sup>21</sup> **UK Fundraising.** *Home page.* (URL: <http://www.fundraising.co.uk/index.html>), 2 September 1997.
- <sup>22</sup> **DejaNews.** *Home page.* (URL: <http://www.dejanews.com>), 10 September 1997
- <sup>23</sup> **Liszt.** *Home page.* (URL: <http://www.liszt.com>), 10 September 1997.
- <sup>24</sup> **TileNet.** *Home page.* (URL: <http://tile.net>), 10 September 1997
- <sup>25</sup> **Government Information Service.** *Home page.* (URL: <http://www.open.gov.uk/>), 10 September 1997.
- <sup>26</sup> **Communities Online.** *Home page.* (URL: <http://www.communities.org.uk/>), 10 September 1997.
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- <sup>29</sup> **Central Computer and Telecommunications Agency.** *Legal issues and the Internet: guideline.* London: HMSO, 1996, 16.
- <sup>30</sup> **Central Computer and Telecommunications Agency.** Ref. 5, 18.
- <sup>31</sup> **Central Computer and Telecommunications Agency.** Ref. 5, 34.
- <sup>32</sup> Interview with Nicki Hastie, Information Officer, Self Help Nottingham, 29 August 1997.
- <sup>33</sup> **Submit it!** Web site marketing primer. (URL: <http://www.submit-it.com/siprimer.htm>), 4 September 1997.

## Chapter 12: Guidelines for the Evaluation of Internet Resources

There is more and more information, and less and less meaning

Baudrillard

### 12.1. Internet Problematics

Internet problematics have been touched upon in the earlier methodology section and survey of electronic self help activities. These problems focus on issues of precision and recall, source and authority, accuracy and currency, and the more subjective relevance and quality. The Internet suffers from a crucial lack of quality control by traditional methods of refereeing, peer review or editing, compounded by the ephemeral nature of much material or the vanity of its publishers. Users are required to perform a series of *filtering* procedures in order to more efficiently satisfy their information needs. As such, Internet searches fit into the more general model of information-seeking behaviour outlined by Wilson. Of pivotal importance is the need to counter the prevailing notion that electronic information resources are too successful and too convenient: users will be tempted to view them as defining the *totality* of available information<sup>1</sup>.

General surfing and unfiltered techniques become less valid as the Internet continues to grow exponentially, and such research methods sit uneasily with a more strategic use of time and resources. This is not to invalidate serendipitous discoveries, which will continue to play a part in locating material, but a strategy based on a more critical thought process offers the time-constrained organisation greater benefits and provides a structure for training staff members to conduct research independently. This quality assessment places greater importance on intellectual endeavour than the speed of retrieval software.

### 12.2. Universal Directories and Search Engines

Coverage tends to be indiscriminate and unfocused, since they are compiled through self-submission, unfiltered recommendation and a robotic trawling process. Lack of pre-selection makes such tools blunt and unwieldy<sup>2</sup>. Display output lacks context, and brief descriptions (selecting lines from anywhere within a document) often give no indication of the actual quality or relevance of a resource.

### 12.3. Reviewing the Reviewers

Services such as OMNI and SOSIG provide evaluative descriptions of the content and quality of resources and represent a vital filtering mechanism, with inclusion itself being an indication of quality. Subject-based guides should have clear resource selection criteria, a statement of aims and intended audience (academic? clinical? educational?), a degree of formality and information professional involvement, an overriding emphasis on content and sensitivity towards access issues. Informative descriptions should be reinforced by subject descriptors or keywords.

## 12.4. Guidelines

Difficulties arise in defining a target audience for self help information. As earlier chapters have demonstrated, condition- or issue-specific groups regularly exchange forms of medical information and advice, in varying degrees of detail, whether it be on side-effects of medication, alternative treatments, or how a disease functions. Self helpers are, by definition, outside the clinical canon, and yet access to clinical information is central to the notion that self help is more than tea and sympathy, revolving as it does around aspects of advocacy, campaigning and the empowerment of individuals in relation to traditional sources of clinical power. If Self Help Nottingham is to serve as a focus or channel for this type of information-seeking, rather than referring to other health information networks in each case, then it must address these issues of the quality of medical information on the Internet. The topic is too vast to provide anything other than a brief overview here, but the central issues are those of *accountability* ("that an identifiable person or group stands behind what it is publishing on the Web and in Internet discussion forums<sup>3</sup>"), *accuracy* and *verifiability*.

### 12.4.1. Core standards [derived in part from several review sources<sup>4 5 6</sup>]

- **Authorship and Authority:** Authors, publishers and contributors, along with their credentials and affiliations, clearly and unambiguously stated. Emphasis on recognised organisations, refereed electronic journals etc.
- **Attribution:** References and sources for content clearly listed, with relevant copyright information.
- **Scope and purpose:** Clear policies, mission statements and indication of intended audience. Does the actual content match the scope? To what level of detail?
- **Disclosure and credibility:** Site ownership, including sponsorship and commercial interests, clearly stated.
- **Currency:** Clear indication of date content was posted and last updated. Is there a stated policy on updating? How frequent?

- Access and design issues: consistent screen layout, sound use of hypertext links and navigational tools, indexing, site maps, search engines, etc. are strong supportive evidence of a resource's quality. Is a text-only version accessible? Is special software required to view full-text resources (e.g. Adobe Acrobat viewer) or multimedia content?
- Content: does the site emphasise substantive content? Is it accurate? Can objectivity be assessed? Is it available in another form or from another source? Is the information factual, or based on opinion?
- Stability: a print equivalent indicates likely stability of electronic sources. Has the source been reviewed elsewhere? (print sources or evaluated electronic sources)
- User support documentation: outlining policy and scope, providing disclaimers, contact details for feedback, interactive forms etc.
- Links from the site: Are links annotated or simply presented as a list? Are they regularly checked and updated? How relevant are they to the scope of the site?
- Charging: Is access to the resource free, or restricted in some way? Is registration required? To what degree of detail?
- Discussion lists: is there a designated moderator? Information on the purpose of the list, access to archives, introduction procedures etc. contribute to assessing the quality of a list (but do not substitute for participation and monitoring).

In practice, so thorough an evaluation is likely to prove difficult to undertake, but guidelines are reinforced by critical thinking in practice, and as self-training builds expertise many of the criteria will become part of the research process. Not all sites will meet all criteria, but the general approach is vital if, at the very least, time and resources are to be more efficiently deployed, or, at worst, cyberquackery is to be avoided.

<sup>1</sup> Anagnostelis, Betsy et al. Thinking critically about information on the Web. *Vine*, 1997, 104, 21-28.

<sup>2</sup> Anagnostelis, Betsy & John Cox. Data on the Internet: evaluating quality, or "Less is More." In: Armstrong, C.J. & R.J. Hartley, eds. *ukolug96@warwick.ac.uk:UKOLUG State-of-the-Art Conference* [Warwick 17-19 July 1996]. London: UKOLUG, 1996, pp. 59-69.

<sup>3</sup> JAMA [Journal of the American Medical Association]. *Assessing, controlling and assuring the quality of medical information on the Internet* [editorial April 16 1997]. (URL: <http://www.ama-assn.org/public/journals/jama/ed7016x.htm>), 19 July 1997.

<sup>4</sup> Smith, Alistair. Criteria for evaluation of Internet information resources. (URL: <http://www.vuw.ac.nz/~agsmith/evaln/index.htm>), 2 September 1997.

<sup>5</sup> Anagnostelis, Betsy & John Cox. Ref. 2.

<sup>6</sup> OMNI. *OMNI guidelines for resource evaluation*. (URL: <http://omni.ac.uk/agec/evalguid.html>), 2 September 1997.

## Chapter 13: Conclusion and Recommendations

### 13.1. Overall

This chapter is presented as a combination of conclusions and recommendations, since the two have been so closely meshed throughout the general evaluative approach of this project: conclusions about the way the Internet can best be utilised in support of a particular aspect of self help activity inevitably contain within them recommendations for the individual case study in question and the voluntary sector in general. Specific recommendations for the development of the site have been covered in Chapter 11 and will only be briefly added to here.

If an overall hypothesis states that the Internet *is* potentially beneficial to self help groups and their development partners, then the overall conclusion is that the hypothesis is true. Such a conclusion is, however, made guardedly. *Some* aspects of the Internet are already being successfully used in the self help support activity, primarily the electronic clearinghouses and online directories covered in Chapters 9 and 10. Other aspects, namely online support groups, present special difficulties in attempting to make clear conclusions: as such, this project has been a process of opening up issues of access, quality and the structures that influence the types of exchanges that take place within such groups. Not all of these issues can be addressed by a single piece of research, so *recommendations for further research* and local pilot projects are incorporated within the following sections.

### 13.2. Strategic issues

The central argument of this project has focused on the potential for developing the clearinghouse model in the UK, adapting it to the local and national context and extending its application to include networks of health and social care professionals. A primary vehicle for such a development is, potentially at least, the Self Help Nottingham WWW Resource Site, a working model of which has been developed, building on the services offered by the team and providing a framework for their ongoing development in collaboration with local and national partners. If such work proceeds in isolation, it is likely to fail through lack of resourcing and commitment, or will lead to unnecessary duplication. The context of IT implementation in the voluntary sector presented in this project is characterised by the need for realistic aspirations in small-scale, non-commercial organisations: low levels of expertise, lack of clarity in defining the concrete ways in which IT can further more general aims, and lack of ongoing technical

support and training produce a sizeable "knowledge gap" which will not simply be bridged by good intentions.

Specific resourcing issues have largely fallen outside the scope of this project. Cost-benefit analyses are always problematic for more generic information services such as those envisaged by the WWW Resource Site (the provision of full-text resources, national and local directories, discussion forum) and firm conclusions about their long-term value difficult to enumerate. The costs of being left outside wider community information initiatives, of missing the opportunity to shape developments from within and ensure a self help perspective is promoted at local and national, are as vital as they are intangible. In raising Self Help Nottingham's profile as a key player in the provision of self help support, research and development and policy formation, at the same time serving as a central focus for networking by researchers and healthcare professionals, the site is both an electronic entity (a collection of pages, an information resource) and a reflection of the team's intention to extend its services following its relaunch.

The team were committed to developing *some* form of Internet strategy, however loosely this was envisaged, and this research feeds into an ongoing review of information policy within the organisation. That the involvement of Internet Service Providers and agencies involved in the development of voluntary/community information networks in Nottinghamshire will be pivotal to the practical ways this model is developed cannot be understated. But to have provided a clearer demarcation of the issues involved, and to have encapsulated them in a "hands-on" and fully-functional site model which can be used to develop information dissemination, research and profile-raising, while at the same time serving as a resource for internal staff training, will hopefully extend the team's knowledge base and give a realistic framework for its future exploitation.

### **13.3. Online self help groups**

Lack of research into the long-term effectiveness of online groups raises questions over the best policy to enable local groups to participate. Although the numerous anecdotal accounts of the benefits of online support are beginning to filter through to more critical studies, there remains a need to provide more in-depth research, perhaps based on comparative analysis of different types of group (USENET and e-mail discussion list, open and moderated) across different conditions. Issues such as optimum group size, the degree of moderation, steering or monitoring by a group leader, the quality and frequency of interaction, levels of participation,



and the way online support relates to self help participation in face-to-face groups, need to be addressed by qualitative and quantitative studies if anything other than an anecdotal picture is to be presented.

An overall conclusion is that moderated discussion lists offer greater security, a sense of group cohesion and identity, an equality in terms of participation, and the ability to respond to difficulties in list administration, in comparison with the immense, unmoderated and unwieldy USENET groups along the *alt.support* spectrum. The case study, however limited, shows that in a very personal sense many of the key features of face-to-face self help (mutuality, serial reciprocity, self-determination, equality, the exchange of experiential knowledge) *are* transferred intact to the larger electronic group format. Such a claim is tempered by the equally personal impact of spiralling list disagreements which often result from an electronic "separation effect", the US bias of group membership, the volume of off-topic discussion and important issues surrounding the validity of medical information exchanged between participants. Such risks point to a central role for Self Help Nottingham in developing a value-added structure that can protect groups from these potentially negative impacts of online activity. This can take several forms: if individuals with Internet access from home wish to be put in touch with online support groups (e.g sufferers of rare syndromes or those for whom participation in face-to-face groups is problematic) Self Help Nottingham can search for groups and perform a form of "vetting" (based on a review of list archives or scope/purpose notes, a period of monitoring). The degree to which this is practicable depends as much on the potential constituency of Internet-enabled self helpers in Nottingham as it does the time and resources available by information section staff.

A more realistic model might include the development of local intranet-based groups linked to discussion lists or bulletin boards, with Self Help Nottingham serving as the central resource "hub" (similar to Support-group.com's bulletin board system in Chapter 10). Such groups offer potential benefits for healthcare professionals to participate and increase their awareness of self help dynamics, and for group leaders to gain practical experience of self help issues in a less intrusive setting. Self Help Nottingham could exploit its role as the enabling interface between professionals and groups by establishing pilot groups, selected from local groups showing an interest in participating in an electronic format as a *supplement* to face-to-face meetings, and continuing their support and development role from far closer quarters than would be possible with international discussion lists.

An additional area of research could involve networked self help activity in Europe. Those valuable perspectives from Germany and Scandinavia, to the fore in the mid-1980s research, are masked by the anglo-centric nature of the Internet, and their contribution to the 1990s electronic landscape would be an illuminating addition.

Such pilot groups, operating under the Self Help Nottingham umbrella, could form the subjects for the sort of research into effectiveness and optimum structure indicated above. This would capitalise on the clearinghouse role which can coordinate research and professional involvement without undermining the groups' self-determining status and the unique ways of coping they offer. Professional involvement must remain group-sanctioned, serving as a resource when required and not in a leadership capacity.

#### **13.4. Site development issues**

In addition to the conclusions and recommendations in Chapter 11, it is important to stress the need to actively engage in promoting the site through traditional and electronic media. The site has developed a number of information tools that will enable the team to target health and social care practitioners, researchers, and international self help contacts. Such strategies need to be reinforced by submitting the site to search engines, publicising its relaunch through subject-oriented discussion lists, and contacting evaluative gateways such as OMNI, SOSIG, Nahat, clearinghouse sites in North America, collections of resources for nurses and General Practitioners, community information resource sites and local public information providers.

However great the potential for providing a new focus for the team's traditional print media (the directory, full-text training materials etc.) and significantly reducing international communication costs, the team's commitment to the integrity of the site must be based on fundamental issues of content and quality. The resources grouped together on the site for the team's internal information use, reinforced by the guidelines in Chapter 12, give an overview of the salient issues in resource evaluation and the use of the Internet to monitor developments in voluntary sector IT initiatives, incorporating aspects of best practice (in terms of design, content and approach) into the site's future structure.

The proposed Forum offers the opportunity to provide the first UK-specific self help discussion list and could serve as a catalyst for national-level policy formation, research and the dissemination of "good practice". Enthusiasm must be set against the realities of such ventures,

which often reach a plateau then fail through lack of input. The forum represents the opportunity to reinforce networks on the ground, to galvanise research and policy activity by offering an additional outlet for publication or highlighting areas of mutual concern.

### **13.5. Final word**

While reinforcing the view that the Internet needs to cross a “quality threshold” before it becomes an essential tool for the voluntary sector, the implementation of Internet-based information and support services is already moving beyond those limitations recently documented in the social care sector<sup>1</sup>.

Constrained by the realities of funding and staff resources, a view nevertheless emerges of a very practical role for the Internet, in its range of forms and structures, to further the claims of self help to be recognised as a primary vehicle for social and economic change. This research represents an attempt to lay the foundations for Self Help Nottingham to make an ongoing contribution to the development of new services for individuals, groups and professionals in a constantly evolving information landscape. The precise shape that contribution will take is difficult to predict, but a locally-adapted WWW-based clearinghouse model provides a shared framework that remains sensitive to self help’s distinctive contribution and the needs of its participants.

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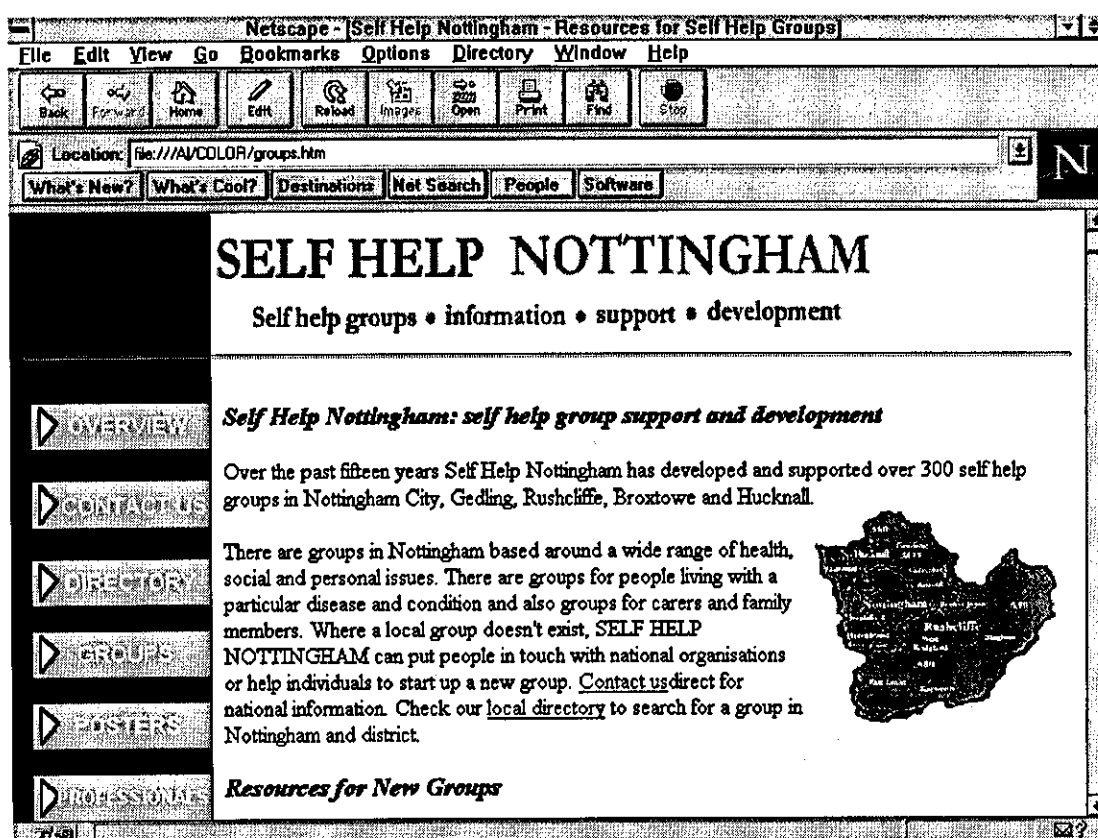
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## Appendix: Selection of printed screens from the Self Help Nottingham WWW site model

Please note: these pages have been resized for this appendix in order to meet binding requirements. In addition, they appear with a blue background margin when viewed through a WWW browser [as the screen capture below shows]



# SELF HELP NOTTINGHAM

Self help groups • information • support • development

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## *Active Alliances for Self Help Support and Development*



A new name, a new set of challenges and opportunities. April 1997 marks the beginning of a new phase in Self Help Nottingham's development as we seek to build on our fifteen years of promoting self help activity, this time as an independent registered charity and a company limited by guarantee.



New challenges, as self help activity continues to establish itself in the evolving landscape of health and social services. New opportunities, as we extend our range of support and development services to new and established groups and develop active alliances with healthcare professionals, the voluntary sector, and international self help organisations.



Our core activities remain focused on supporting self-help in Nottinghamshire and include



- helping groups in all stages of their development, from set-up to fully-functional self help group
- providing ongoing support and training to enable groups to attain their goals
- to provide coordination and links between groups and potential members
- to publish and maintain the *Directory of Self Help and Carers' Groups*
- providing HelpBox database information on local groups to Trent Healthline
- forging links between self help groups and professionals to encourage cooperation
- publications, training and consultancy on self help issues
- information enquiry services
- fundraising and funding application support and advice
- poster design and publicity materials for groups
- free meeting place for new and established groups
- local advertising liaison



As the use of Internet technology in voluntary organisations and community networks grows, we aim to develop national and international links and provide a forum for discussion on self help policy and related issues. This site will serve as a local, national and international resource for self help groups and their support agencies.



### Copyright Statement/Disclaimer. Please Read!

This site was originally designed by Matt Clements, Loughborough University [1997]

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E-mail: [selfhelp@globalnet.co.uk](mailto:selfhelp@globalnet.co.uk)

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# SELF HELP NOTTINGHAM

Self help groups \* information \* support \* development

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## ***Web Resource Overview: How to Navigate around the site***



Use the grey button bar to the left of the screen, the hypertext link menu at the foot of the page, or follow links within individual pages. The site will continue to expand on its existing sections, but the navigational architecture will remain consistent throughout its future development.



**Contact Us** Contact details, a "how to find us" map, e-mail feedback form etc.



**Directory** Search the online Directory of Self Help Groups in Nottingham and District



**Groups** Information on starting and running a self-help group, with full-text resources



**Posters** The virtual display board! Publicise your group's activities, or download posters for your surgery or community centre!



**Professionals** Information for professionals with an interest in supporting self help groups



**Publications** Full list of Self Help Nottingham publications [and order form!]



**Training** Details of our training courses for self help groups and their allies



**Forum** Join our discussion list on self help support and development issues



**Organisations** Links to evaluated sites produced by self help development partners



**Resources [internal]** Internet links to evaluated sites for Self Help Nottingham's information function



**Site Sponsors** Acknowledgements for site funding support



**News** Hot off the presses! Access our latest newsletter, activity updates etc. And visit our New Home Appeal too.



**National Directory** Read about our latest publication, *Connect Self Help UK* and access information on self help groups in your area.



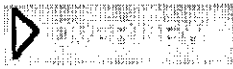
**Home Page** What site would be complete without it? Read Self Help Nottingham's mission statement.

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[[Overview](#) | [Contact Us](#) | [Directory](#) | [Groups](#) | [Posters](#) | [Professionals](#) | [Publications](#) | [Training](#) | [Forum](#) | [Organisations](#) | [Resources](#) | [Sponsors](#) | [News](#) | [National Directory](#) | [HomePage](#)]

# SELF HELP NOTTINGHAM

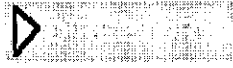
Self help groups \* information \* support \* development



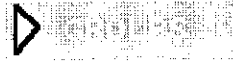
## Contact Us



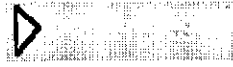
Write to us at:



**SELF HELP NOTTINGHAM**  
**20 Pelham Road**  
**Sherwood Rise**  
**Nottingham NG5 1AP**



Telephone:



Information Line **0115 969 1212** (Mon-Fri, 09.00 - 13.30)



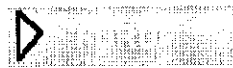
General Enquiries **0115 969 1514** (Mon-Fri, 0900 - 17.00)



Or Fax us on **0115 960 2049**



Alternatively, send us an e-mail!



We welcome comments about our site, so send any suggestions to:  
[selfhelp@globalnet.co.uk](mailto:selfhelp@globalnet.co.uk)



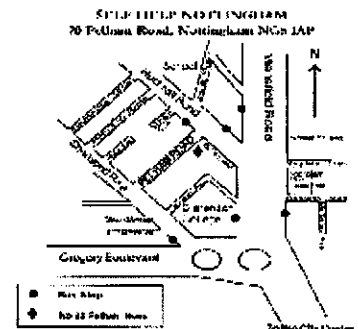
The office is on the ground floor with full access from Pelham Road for people using wheelchairs. Parking available outside this entrance. Further unrestricted parking on the north side of Pelham Road and on nearby Hamilton Road and Alexandra Street. [Click on the map to print a larger scale copy.]



Frequent buses to and from the city centre, just over a mile away.



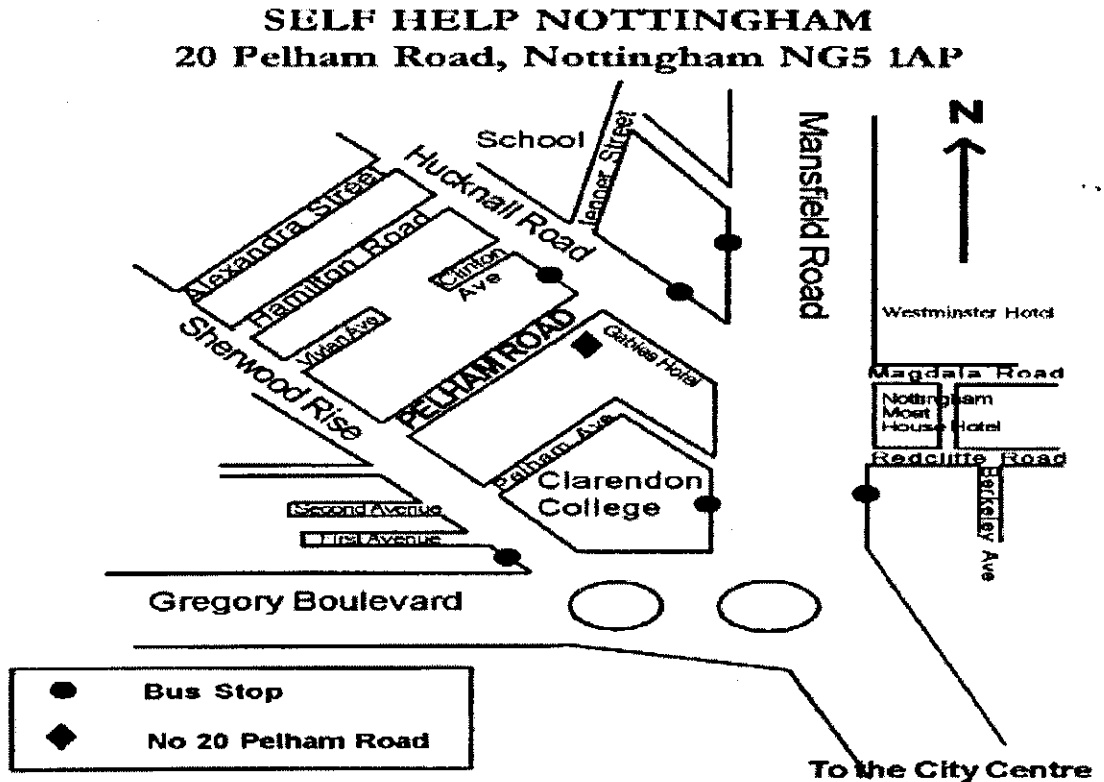
- From Trinity Square, via Mansfield Road and Hucknall Road
- Bus Numbers 16, 17, 18, 19, 88, 99
- From Market Square, via Mansfield Road
- Bus Numbers 55, 56, 57, 58, 59, 90



[\[Overview\]](#) | [\[Contact Us\]](#) | [\[Directory\]](#) | [\[Groups\]](#) | [\[Posters\]](#) | [\[Professionals\]](#) | [\[Publications\]](#) | [\[Training\]](#) | [\[Forum\]](#) | [\[Organisations\]](#) | [\[Resources\]](#) | [\[Sponsors\]](#) | [\[News\]](#) | [\[National Directory\]](#) | [\[HomePage\]](#)

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# SELF HELP NOTTINGHAM

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## ***Self Help Nottingham: self help group support and development***



Over the past fifteen years Self Help Nottingham has developed and supported over 300 self help groups in Nottingham City, Gedling, Rushcliffe, Broxtowe and Hucknall.



There are groups in Nottingham based around a wide range of health, social and personal issues. There are groups for people living with a particular disease and condition and also groups for carers and family members. Where a local group doesn't exist, SELF HELP NOTTINGHAM can put people in touch with national organisations or help individuals to start up a new group. Check our [local directory](#) and search for a group or [contact us](#) direct.



## ***Resources for New Groups***



[this is an excerpt from [Starting Off: information and ideas for new self help groups](#)]



### **Section 1: The First Steps**



What do you do first?



Most people have found it best to spend some time taking a few cautious steps before they start, rather than rushing to begin. Here are the first few steps you could take:-



#### **Step 1: Stop and Think**



Take some time to think if you really want to start a group.



If you need one mostly to help with your own problems, you could ask yourself:-  
Why do you want one? How badly do you need it? Could you get by with other forms of help?



On the other hand, you may be thinking more of starting a group so that people who are newly experiencing a problem can get help. You remember what it was like for you and you don't want other people to have to flounder in the same way. You'll probably also get a lot out of it yourself, but the emphasis of the group may be different. You could ask yourself:-

- Why do you want to help other people?
- How important is it to you to do so?
- Are you far enough on in coping with your own situation?
- Could starting a group make you feel worse, not better?
- What benefits might you get out of it?

Don't worry whether you can start a group or not. First consider seriously how much you want to and why.

Think about possible obstacles.

- Starting a group will mean demands on your time, your energy and your

money.

- It may mean intrusion into your home - by telephone calls if not by people themselves.
- It could well affect your family.
- Starting a group can mean having to cope emotionally with other people's problems as well as your own.

Think about the advantages too.

- Your life could be changed completely - for the better.
- You may get surprising amounts of help yourself.
- You may make a new set of supportive friends.
- You could become fulfilled through being able to help someone else.
- You could find yourself doing all sorts of things you never dreamed you could do.

Weigh up the possible demands on you on the one hand and the likely benefits on the other.

Think of the next six months ahead of you. Could you put some time, energy and commitment into a new group for about that length of time? If you are doubtful, then it might be better to shelve the idea for a bit or to approach the problem in a different way.

You still want to do it? Then take the next step.

## **Step 2: Find Some People who Think Like You**

You will need to put some effort into starting a group, but you need not take it on alone. In fact, it's better not to.

Find a few other people who are interested in starting, not simply belonging, to a new group. Two or three is enough, even one other person will do. Try to make it clear at this stage that the group is not yet active and that you're looking for people willing to help in getting it started.

How might you find your first few people? Ask yourself some questions again.

- How common is the situation you're in?
- Do you want a group based on one neighbourhood or one village?
- Would it be better to cover a whole town, city or an even wider area?
- Are you likely to want to work closely with professionals in the health and social services? If so, they could be helpful in finding like-minded people.

You could produce a simple poster asking if people would be interested in helping to start a group. Use the Checklist to see ideas you might employ to find other people.

## **Step 3: Get Together**

When you have found the first few people, get together for a chat. Meet several times if you feel the need. There's no need to rush.

If it's convenient, meet in someone's home to start with, or find a free, quiet place that is accessible for all members. (There's more about meeting places in Section 4.)

One thing you'll need to talk about is how much you'll expect people to contribute to the group, not necessarily money, but in commitment and time. This is important: self help groups are not groups where you do things for people all the time. They work best if members share responsibilities and jobs, make decisions

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***Self Help Nottingham Poster Gallery: a Virtual Display Board for Self Help Groups***



Self Help Nottingham offer assistance in poster design and printing for new groups, as part of their support, development and promotion activity.



This Web Poster Gallery serves as an opportunity for groups to publicise their activity within the Nottingham NHS Intranet, and can be used by G.Ps and other healthcare professionals to promote the work of groups in their practice or hospital setting.



The following pages can be printed as single A4 posters: Remember to use the BACK arrow on your browser to return to this page!



**Local Groups**



SPYCAT: for young autistic children, their families and carers



Mental Health Self Help Group



Step Mum



(SAM) Sexually Abused Men



This resource will continue to expand as more groups add their posters to the noticeboard.



Contact Self Help Nottingham if you want your group's poster to be included in future updates.



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## Resources for Primary Care professionals



### *A self help group for your patient? Guidelines for G.P. Practices*

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Produced jointly by the Family Health Services Authority and Self Help Nottingham © 1993



#### Contents



Foreword Introduction What is a self help group? Common doubts



Making the link Promoting better relations Summary



#### Foreword



Primary Care encompasses a diverse range of professionals and sources of help with patient care. With the ever increasing demands placed on our limited resources, it is important that we utilise the appropriate sources to their maximum potential.



An often underused resource of expertise is people who have themselves suffered from a disease and have acquired information and knowledge which has helped them deal with their illness.



Self Help Groups can, therefore, act as an invaluable source of help to patients and doctors in an educational and supportive capacity. They also encourage patients to play a more active role in their own illness.



We need to appreciate that there may be limitations of such groups and perhaps areas of conflict even, but to some extent G.P.s can reduce this problem by sharing their concerns and ideas.



It is our role as G.P.s to be aware that Self Help Groups can offer additional help to our patients and to ensure that our patients are aware of the group's existence and roles.



*Dr. Kam Kaur General Practitioner*



#### Introduction



As Care in the Community increasingly emphasises the needs not only of patients but also of carers, it is important that GPs and practice staff are aware of what is available in the community.

Self help groups form a large informal network for people coping with chronic illness, disability, those caring for friends and relatives, for the bereaved and for people who may be isolated.

This resource has been updated to help promote links between GPs and self help groups and to provide information on how to contact groups in your area.

[\[Back to Contents\]](#)

#### What is a Self Help Group?

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## Publications



Self Help Nottingham publications



### Directory of Self Help Groups in Nottingham and District



- Updated annually. 16th edition [1996/97]
- Price: £3.50



Includes details of over 200 local groups. Provides useful, up to date information for individual members of the public, library and information workers, the media, voluntary organisations and health and social services professionals. Additional sections in the directory list professionally-run support groups and other useful organisations.



Free copies available to Nottingham Health District NHS professionals [includes staff of the Nottingham Health Commission, NHS Trusts, GPs, opticians and pharmacists.] Orders may be sent to Self Help Nottingham through the NHS internal mail system. Contact Self Help Nottingham for details of discounts for multiple copies.



[Order Form]



### Starting Off: information and ideas for new self help groups



- 2nd edition. 1994
- Price: £7.50 [+£1.00 p&p]
- Format: A4, card cover, wire bound [48pp]



Self Help Nottingham's starter pack for new groups has proved a valuable resource for many groups over the years. This new edition builds on those experiences. Included are ideas and information about: initial stages - setting aims and objectives - group activities - meetings - money matters - publicity - other sources of help - how to make groups work - national contacts section



Essentially it is a useful tool for people thinking about setting up a group, but also for community development, social work or health practitioners supporting groups in this process. Information is applicable to groups in any part of the country.



[Order Form]

### Giving Talks to Professionals

- 2nd edition. 1994
- Price: £1.60 [+£0.50 p&p]

### A Self help group for your patient?

- 2nd edition. 1993
- Price: £1.00 [+£0.40 p&p]

Guidelines for General Practitioners

Connect Self Help UK

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## Training



SELF HELP NOTTINGHAM provides



- high quality national training events
- conferences
- consultancy
- individually tailored workshops



designed to meet the specific training needs of staff teams and agencies



Training aims to:



- Identify good practice in the field of self help
- Provide opportunities for skill sharing and development
- Provide models of support and ways of working creatively with self help groups



**Self Help Works** A series of training initiatives for professionals in health, social services and the voluntary sector.



**Self Help Groups: Ethics and Good Practice**



- 7th October 1997
- Venue: Central Nottingham
- Cost £65.00



**Self Help Groups: Handling Difficult Situations**



- 20th January 1998
- Venue: Nottingham
- Cost: £65.00



**Self Help Groups: Moving from Professionally-led to User-led Groups**



- 24th March 1998
- Venue: Nottingham
- Cost: £65.00



For further details and an application form for these courses, [contact us!](#)



**In the pipeline...**

A series of Saturday morning workshops on Committee Skills, including:

**The Role of the Committee Secretary**

- 20th September 1997 [10.30-12.30]

**Help! I've just been elected onto the Committee!**

- October 11th 1997 [10.30-12.30]

**Confidence Building for Chairs of Self Help Groups**

- November 15th 1997 [10.30-12.30]

Cost: £5.00 per workshop per person. [Contact us](#) to book your place!

**Basic Listening Skills**

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## ▶ Internet Research Tools:

### ● Gateways and Subject Guides

▶ Rather than rely on the eccentricities of all-encompassing search engines, the following sites serve as organised gateways to information resources connected with self-help support activity.

▶ OMNI OMNI is a gateway to Internet resources in medicine, biomedicine, allied health, health management and related topics. Comprehensive coverage of UK resources in this area and access to the best resources worldwide. By a process of selection, evaluation and description the collection is continuously updated.

▶ NHS Confederation Gateway NAHAT-supported site with alphabetical subject list of links, from Alternative Medicine to UK Medical Schools.

▶ PubMed The US National Library of Medicine online version of Medline, a leading source of clinical research across many health subjects. Advanced search enables accurate, targeted enquiries. A key source of information on research into the *effectiveness* of self help groups, given the need to inform clinicians of the benefits of self help activity.

▶ SOSIG Social Sciences Information Gateway. UK-based academic site. Sporadic self help coverage

▶ PsychWeb Self-Help Psychology Resources Collection of mainly US non-commercial sites subdivided by topic. Strong psychology/mental health emphasis.

### ● UK Self Help Directory Initiatives

▶ Northern Advisory Group on Disability Directory of Self Help and Support Groups 1997. Pioneering site that offers non-searchable database of groups in the North East, subdivided by broad topic, region and alphabetical listing. Site set to expand on pilot project to publish local group web pages.

▶ INFOCAM Web-searchable Community Information Database from Cambridgeshire County Council. Contains details of over 5000 local community, voluntary and self-help groups, clubs and societies, and other local resources and facilities.

### ● International Self Help Support Organisations & Clearinghouses

▶ These serve as useful models for the introduction of Internet resources in support of self-help activity in the United States.

▶ Self Help Network of Kansas Excellent example of high-content web resource, with definitions, bibliographies and downloadable full-text training materials in the SHARE library.

▶ Self-Help Sourcebook Online The American Self-Help Clearinghouse site. A pioneering resource developed by Edward Madara. Directory covers US groups only. Despite the US emphasis, contains valuable collections on "Research on Self-Help Groups" and starting online groups.

▶ Illinois Coalition Includes online directory of local groups.

▶ Champaign County Some full-text resources.

▶ Self-Help Connection [Nova Scotia] Basic site. Minimal content.

▶ El Paso area groups Contact details only.

### ● International Self Help Research

▶ Partnerships for Networked Consumer Health Information Conferences Collection of transcripts of

conferences and workshops, some with self help emphasis. US bias throughout.

Support Group-com. Alphabetical list of condition-specific links to bulletin boards, online support groups and web resources [subdivided into national, international and local groups; professional resources; general information; alternative therapies etc.]

Storm King's articles and links Research on the psychology of virtual communities

- **UK Community Development/Voluntary Sector Organisations**

UK Primary Care Requires registration for full access. As well as grouping together resources for primary care practitioners, offers a brief [flawed?] list of self help agencies. Room for improvement.

National Institute for Social Work Well organised small-scale site with full-text resources. Note the Getting Voluntary Organisations Online project.

Help for Health Trust Market intelligence? Helpbox contact? Poorly orchestrated site but vital to monitor their movements in the community development sphere.

UK Fundraising Collection of resources, links and case studies on Internet fundraising

National Lottery Charities Board Vital, direct source for funding initiatives information.

Mental Health Foundation UK charity with brief mental health service directory, downloadable leaflets

Community Care Hosts condition-specific charity pages, among them the UK-ME Web, as well as an alphabetical index of links to Web health resources.

CharityNet Charities Aid Foundation-run service for charities, donors and companies

VOIS Voluntary Organisations Internet Server. Hosts charity sites, provide resources on site set-up and promotion etc. Volunteers Noticeboard.

NCVO National Council for Voluntary Organisations. UK umbrella organisation with over 840 voluntary organisations as members, the NCVO promotes and supports the voluntary sector. Site contains press releases, details of services, publications etc.

Disability Nottinghamshire

- **Examples of Condition-Specific Materials**

Self-Help and Support Groups for Parents of Children with Special Needs in Canada Report from Child & Family Canada

Give Hope Brain Tumour resources Volunteer-authored list of contact details of organisations for brain tumour patients and carers.

- **Locating Newsgroups & Discussion Lists**

Liszt Type "self help" in search engine to obtain the following discussion list: SLFHLP-L. You can join this group by sending the message "sub SLFHLP-L your name" to listserv@listserv.utoronto.ca

DejaNews Search for USENET groups

TileNet Search for USENET groups and discussion lists

Mailbase Locate academic discussion lists

Emotional Support on the Internet List of links to USENET newsgroups, discussion lists.

- **Legal Issues and Site Maintenance**

Data Protection Registrar

Copyright Licensing Agency



[Edward Barrow's Unofficial Internet Copyright Pages](#)

[Metronet links](#)

[Bobby HTML validation for all browsers](#)

[Yale C/AIM Style guide](#)

[Submit-It Post site to major search engines](#)

[Hensa HTML validation](#)

- **Communities, Telematics and Virtual Villages**

[Government Information Service](#) Links to government departments, local government, health authorities etc.

[Communities Online](#) Major site for community networks and telematics, with full-text articles, research, links

[BT Labs](#) Community networks resources

[Tagish Ltd.](#) Key players in European Information Society projects. Involved in the NAGD pilot project [see above]

[PERIPHERA European project](#) [and [here!](#)] European-funded project aims to provide "access to technologies for exploitation of 'new opportunities for working' through 'new ways of working' via self-help."

- **Self Help Publishers Online**

[SAGE publishers](#)

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[[Overview](#) | [Contact Us](#) | [Directory](#) | [Groups](#) | [Posters](#) | [Professionals](#) | [Publications](#) | [Training](#) | [Forum](#) | [Organisations](#) | [Resources](#) | [Sponsors](#) | [News](#) | [National Directory](#) | [HomePage](#)]

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## *A new home for SELF HELP NOTTINGHAM...*



We are planning to re-locate to a city centre site later in 1997. A move will enable us to reach a greater number of people, link us more closely with other helping agencies, and help us to extend and improve our quality of service. We need local support from Nottingham people, self help groups, local authorities, the business community and local charitable trusts to help us reach our goal.



We plan to provide an accessible meeting space for new self help groups, with kitchen facilities, plus an open plan office and information and resource area. As well as seeking funds to refurbish the premises we are also approaching individual and corporate donors to contribute both cash donations and gifts in kind. In particular, we are planning to provide a ground floor fully accessible meeting room and kitchen for groups. We need to build (i.e. partition a currently open plan space), furnish and equip these rooms.



For example, a fully equipped kitchen would include table, chairs, crockery and utensils, kitchen equipment such as a dishwasher, microwave, fridge, storage space and floor covering at a minimum cost of £3000.



A donation to our appeal would contribute greatly to achieving our aim. Any donations will receive due acknowledgment and publicity (unless otherwise requested) through a special edition newsletter and in our annual report.



Contact Self Help Nottingham for further details on how you might contribute.

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[[Overview](#) | [Contact Us](#) | [Directory](#) | [Groups](#) | [Posters](#) | [Professionals](#) | [Publications](#) | [Training](#) | [Forum](#) | [Organisations](#) | [Resources](#) | [Sponsors](#) | [News](#) | [National Directory](#) | [HomePage](#)]

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## Connect Self Help UK



*A directory of locally based voluntary organisations offering support to self help groups*



- Published by Self Help Nottingham [April 1997]
- ISBN: 0 9521031 17
- Price: £9.95
- Paperback: matt laminate cover, 316pp perfect bound



**Connect Self Help UK** is an easy-to-use reference of voluntary sector development agencies offering support to people setting up or working with self help groups. Produced in a user-friendly format, the A-Z listing gives a quick guide to services on offer from organisations in the UK.



Compiled from postal questionnaires and follow-up research, this directory is the most complete listing to date. There are very few specialist self help workers or organisations, making it all the more important to identify other sources of support, particularly in rural areas and for specific communities. Where possible, agencies working with black and minority ethnic groups and mental health service users have been identified.



**Connect Self Help UK** will prove a valuable information resource for community development workers, councils for voluntary services, volunteer bureaux, national organisations and public libraries. It will help practitioners to put people in touch with support agencies local to them. Also included in the directory are other useful contacts and names of international self help support agencies and clearinghouses.



This publication has been made possible with the support of grant-aid from the Department of National Heritage.



[Order your copy now!](#)



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## Site Sponsors

Self Help Nottingham wishes to acknowledge the following organisations who have supported the production of this web resource



- Broxtowe Borough Council
- Halifax Building Society
- Nottinghamshire County Council Partnership Fund
- Nottingham Healthcare NHS Trust
- Nottingham Community Health NHS Trust

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