

# Beyond the therapeutic: A Habermasian view of self-help groups' place in the public sphere

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**Abstract** Self-help groups in the United Kingdom continue to grow in number and address virtually every conceivable health condition, but they remain the subject of very little theoretical analysis. The literature to date has predominantly focused on their therapeutic effects on individual members. And yet they are widely presumed to fulfil a broader civic role and to encourage democratic citizenship. The article uses Habermas' model of the public sphere as an analytical tool with which to reconsider the literature on self-help groups in order to increase our knowledge of their civic functions. In doing this it also aims to illustrate the continuing relevance of Habermas' work to our understanding of issues in health and social care. We consider, within the context of current health policies and practices, the extent to which self-help groups with a range of different forms and functions operate according to the principles of communicative rationality that Habermas deemed key to democratic legitimacy. We conclude that self-help groups' civic role is more complex than is usually presumed and that various factors including groups' leadership, organisational structure and links with public agencies can affect their efficacy within the public sphere.

*Social Theory & Health* (2013) **11**, 59–80. doi:10.1057/sth.2012.14;

published online 10 October 2012

**Keywords:** Habermas; self-help group; health citizenship; public sphere

The online version of this article is available Open Access

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## Introduction

The number of self-help groups has proliferated over recent decades with more than 23 000 now believed to be in operation in the United Kingdom (Elsdon *et al*, 2000), thus making them an important social phenomenon. Furthermore, their widely perceived civic role gives them currency within academic and political discourse, which in recent years has seen the regeneration of the civic or public sphere as an issue of fundamental importance in advanced Western democracies (Anheier, 2004; Alexander, 2006; Daly and Howell, 2006). However, despite this relevance to the current debate, comparatively little is known about self-help groups. Indeed the term 'self-help group' can still elicit confusion and can mean many things to different people. Even within academic studies there is a lack of agreement about its definition. And therefore any research or theoretical analysis needs to begin with a clarification of what is included within this concept. Self-help groups grew out of the civil rights movements in the 1960s and 1970s (Williams, 2004) but since that time have evolved into a very different looking phenomenon. In their current form, they tend to emerge in response to a specific health condition, or a social situation with the potential to affect health and well-being, such as bereavement or divorce (Chaudhary *et al*, 2010). Hence they are frequently described under the heading of 'single issue group' (Munn-Giddings, 2003). Despite grey areas at their definitional boundaries though, it is possible to glean some core characteristics the possession of which would be broadly agreed upon as constituting a genuine self-help group. These groups are essentially associations of individuals who meet, either face to face or virtually, on a voluntary basis, in response to a shared health or social problem or situation; control of the group rests with its members rather than an outside agency; and mutual, peer support is provided within the group (see for example Wilson, 1994; Borkman, 1999; Steinke, 2000; Baldacchino and Hussein Rassool, 2006).

However, beyond these core features self-help groups display a 'staggering diversity' of forms (Munn-Giddings, 2003). They can range from small groups that meet in each others' homes to large national organisations. The support they offer may be through close, friendship-type relationships or within rigid rule structures, such as within '12-step' groups like Alcoholics or Gamblers Anonymous, and, increasingly, through electronic media. Although they are still often described as 'anti-bureaucratic' (Borkman, 1999) and egalitarian, their structures vary from totally informal to fully constituted charities. Epistemologically they are usually referred to as grounded in the 'experiential knowledge' of their members that is shared through the expression of members' narrative histories and the process of social learning (Rappaport, 1994; Borkman, 1999). Again, though, this may vary widely from group to group.

Their purpose and 'orientation' spans a range from those groups that appear to be wholly 'inner-focused', that is on the specific concerns of their members, to those that focus outward, through advocacy or campaigning, on deficits within the broader society (Munn-Giddings, 2003). The task of defining self-help groups is further complicated because these more outer-focused groups often exist in a state of ongoing evolution in terms of their aims and purpose. This means their boundaries can begin to blur with other types of group such as service user organisations, whose primary role is the delivery of health services rather than mutual support (Borkman and Munn-Giddings, 2008), or health social movements, whose primary aim is to effect political change (Brown *et al*, 2004).

The majority of self-help group literature has focused on their therapeutic effects on individual members and has conceptualised them within a human services framework (Emerick, 1991; Rappaport, 1994). However, some broader, more community-oriented analyses have been undertaken. For example, self-help groups have been approached from a voluntary action perspective (Karlsson *et al*, 2002), within organisational theories (Medvene, 1985) or as sites of identity and norm creation through members' development of unique group narratives (Rappaport, 1994). In addition, a Habermasian framework has been adopted as a means through which to explain self-help groups as a category of social movement (Kelleher, 2001; Scambler and Kelleher, 2006). These models have shifted attention towards the social context of self-help groups, their organisational forms and the nature of the communication occurring within them. However, despite these studies, it remains the case that limited attention has been given to this type of broader theoretical approach to self-help groups' study. At the same time, however, there is a widely held presumption that self-help groups play an important role in civil society (see for example Ben-Ari, 1998; Damen *et al*, 2000; Elsdon *et al*, 2000; Munn-Giddings, 2003; Williams, 2004). Other bodies of literature including sociology and voluntary sector studies have also alluded to this link. Sociology offers contrasting views about self-help groups. On the one hand, they are said to contribute towards a retreat from civic life as people focus increasingly on their own narrow concerns (Bauman, 1999; Marcello and Perrucci, 2000). In this view, self-help groups feed into a culture in which problems are removed from the public sphere and addressed solely in private spaces. The alternative view is that self-help groups positively affect democratic behaviour (Giddens, 1991, 1998; Anheier, 2004), providing spaces for reflection on the reality of current politics, with a focus on questions of identity, ways of living and personal services rather than the broad redistributive questions that had been central to politics in the past (Giddens, 1991, 1998). Similarly, it is believed that the growth of self-help could reverse a commonly perceived decline in the civic role of traditional voluntary sector



organisations (Whelan, 1999; Nash and Paxton, 2002; Fyfe and Milligan, 2003). This civic decline has also been observed more broadly in both political and academic spheres. In recent years, there has been a pervasive belief that the quality of the public sphere has deteriorated in advanced societies (Habermas, 1989; Alexander, 2006) and that a broad range of social problems such as community dysfunction and voter apathy are symptoms of this trend (Anheier, 2004; NEF, 2010).

The perception of this degeneration has stimulated a search for new channels through which citizenship and democracy can be bolstered and the public sphere revitalised (Habermas, 1989, 1996; Daly and Howell, 2006). A number of UK health policy initiatives, for example community consultation processes (ODPM, 2005), the Expert Patient Programme and the Self Care (DoH, 2006a), and Big Society agendas, incorporate specific aims and procedures intended to 'revitalise democracy through increased civic action within the community' (Cameron, 2010). These policies rely on processes and practices, such as peer expertise and grassroots participation, that have long been seen as constituting the heart of self-help. At an academic level, attempts have been made to update citizenship theories in ways that reflect modern politics' concern with individual lifestyle issues, in particular, health (Zoller, 2005; Landzelius, 2006). This would suggest that self-help groups, as grassroots organisations, the majority of which address specific health conditions, might be a good place to begin the search for these new channels of civic life. However, the broader effects and community-based aspects of self-help groups remain under-researched and under-theorised (Borkman, 1999; Steinke, 2000; Hatzidimitriadou, 2002). And those commentators who postulate a role for self-help as a means through which to revitalise the democratising function of the voluntary sector appear to have based this view largely on presumption rather than detailed analysis or empirical study.

Furthermore, self-help groups have not played a central role, in comparison to health advocacy groups and social movements, within the developing body of theory that links health to citizenship and democracy (Brown *et al*, 2004; Zoller, 2005). When self-help groups have received attention within this field they have tended to be conceptualised as a 'limited' form of new social movement (Kelleher, 2001, p. 139). Kelleher (2001) and Scambler and Kelleher (2006) adopt a Habermasian approach to the explanation of self-help groups as a type of social movement and as such offer a valuable discussion about their effects at the civic level. Their accounts also illuminate the many shared characteristics and extensive blurring between these two types of association. However, they concede that self-help groups do not fully 'qualify' as social movements but merely form 'part of their culture' (2006, p. 228). It is not however always clear as to where the boundary between true and limited social movements will lie. Self-help groups are differentiated from social movements

on the grounds that they are ‘not political’ except in oblique ways. But Kelleher (2001, p. 122) goes on to say that health social movements themselves are not political ‘in a direct sense’. Self-help groups are regarded as lacking the ‘politicised’ element (Brown *et al*, 2004, p. 60) that would grant them full social movement status. Even Melucci, whose ideas about new social movements’ latency and existence as part of everyday life, appears to closely reflect self-help groups, brackets ‘emotional support’ groups – which sound archetypally self-help – alongside ‘sects’ as somehow deficient in terms of collective action (1989, p. 72). Conceptualising self-help groups in this way may be a factor in the lack of clarity in this area and thus may not fully account for their unique qualities. The current article therefore intends to approach self-help groups in their own right rather than as a form of social movement and to contribute to the debate about their civic role through reconsidering the self-help literature in the light of Habermasian theory.

We shall consider the extent to which self-help groups with different structures, orientations and purposes may fulfil or fall short of various criteria that are believed to confer legitimacy within the public sphere. And we shall use this preliminary review to raise questions for future research in order to address the lack of empirical evidence in this area (Dahlgren, 2002; Scambler and Kelleher, 2006). In doing this, we also aim to contribute to ongoing debates about the relevance of Habermas’ work to current policy, practice and theory in health and social care (Scambler, 1987, 1998; Hodge, 2005; Godin *et al*, 2007; Garrett, 2009).

The discussion will take place within the context of current UK health and social care policy and practices that have begun to operate within the areas traditionally occupied by self-help groups.

The article will begin with a broad overview of those aspects of Habermas’ public sphere most germane to the understanding of self-help groups, and the reasons why his ideas are still relevant to current debates. We shall then reconsider the existing literature about self-help groups in relation to this model of the public sphere. This will entail discussion of the extent of self-help groups’ independence; the nature, quality and topics of conversations within them; the levels of internal democracy and inclusivity they possess; and the effects they may have on individual autonomy. We conclude with a discussion of what can be learned about self-help groups by approaching them from this theoretical perspective, and what questions it raises for future research.

## The Habermasian Perspective

The article will focus its questions about self-help groups through the lens of Habermasian theories about a communicative public sphere. In doing this,



we hope to contribute to a growing interest in using Habermasian theory as a means of conducting analysis and unpicking the democratising claims of contemporary practices in health and social care (Houston, 2002; Hodge, 2005; Hayes and Houston, 2007)

From a Habermasian perspective, the public sphere or civil society is actually a part, although an institutionalised one, of people's more private relationships, alongside family and friendships, that form what he referred to as the 'lifeworld' (Habermas, 1984, 1996). This is contrasted with the 'system' that comprises the formal political and economic spheres of activity. It is through unimpeded communication and the free flow of ideas within the former that individuals are able to develop their moral agency, autonomy and unique individual voice. The ideas and opinions formed in the lifeworld can then become politicised through peoples' interaction within institutions and associations operating in the public sphere. A vital function of the public sphere is therefore to maintain at least some separation between these two worlds (Habermas, 1989, 1996). Without defending its independence, the lifeworld will inevitably, due to the far greater power of the system, be encroached upon and 'colonised' (Scambler, 1998), losing its ability to nurture personal autonomy and agency, and hence resulting in greater passivity and dependence on the system and decreased capacity for individual, unique input into public discourse. It should be noted that although Habermas sees both the 'powers of the state and the forces of capitalism' as inherently threatening to the lifeworld (Williams and Popay, 2001), this article, due to the constraints of space, will concentrate on the latter. Self-help groups are understood to develop in unique ways in response to their national political economy, in particular with regard to the role of the state as a welfare provider (Karlsson *et al*, 2002). Therefore, as the UK state, despite moves towards privatisation, is still by far the biggest paymaster of welfare services including the NHS, the effects of its actions in the civic domain warrant attention no less than those of the market economy.

For Habermas, the public sphere comes to life through the process of communicative rationality (1984). This has led his critics, many rooted in feminist traditions, to accuse him of focusing solely on the attainment of rational consensus (Graham, 2008; Karppinen *et al*, 2008) forcing particularist or private interests out of the picture (Benhabib, 1992; Graham, 2008). Feminists have argued that Habermas' emphasis on universal, moral questions serves to invalidate and devalue personal, ethical issues (Benhabib, 1992). However, Habermas (1996, p. 314) states that 'visions of the good life' are indeed the types of issue over which struggles in the public sphere should take place. Coupled with his emphasis on inclusiveness and egalitarianism (1989), this suggests that the type of universalism that operates in the public sphere is based as much in notions of respect for individual dignity and worth as in narrow, procedural issues of

justice (Benhabib, 1992), and thus it does not amount to an automatic bar to 'particularity' (Landes, 1995, p. 98). Habermas' recognition of the individual's standpoint and experience supports this reading of his work:

The political public sphere can fulfil its function only insofar as it develops out of the communication taking place among *those who are potentially affected* ... systemic deficiencies are experienced in the context of individual life histories ... *assessed in terms of one's own life history*. Problems voiced in the public sphere first become visible when they are mirrored in personal life experience. (1996, p. 369; original emphasis)

Critics also assert that Habermasian rationality entails formal logic and tidy, disembodied, unemotional forms of speech that serve to reinforce power differentials (Hodge, 2005; Karppinen *et al*, 2008). However, Habermas gives plausibility to a view of the informal public sphere as a 'wild' and 'anarchic' complex (1996, p. 307) and stresses the role of 'everyday' language (1996, p. 360) and vernaculars as a means of combatting social status and attaining equality (1989) – indeed in the nascent public sphere in Germany, associations were 'preoccupied with the native tongue, now interpreted as the medium of communication and understanding between people in their common quality as human beings – nothing more than human beings' (1989, p. 34).

The key to communicative rationality is thus neither narrowly conceived universalism nor linguistic formality – rather it refers to the fundamental necessity of open-ended dialogue. This communicatively rational speech, unlike that which furnishes the strategic rationality of the system cannot be used as a means to justify and legitimise pre-existing decisions or ends. It must reach its conclusions and outcomes solely through the quality of competing claims and arguments and never through the abuse of power or the exclusion or denigration of any relevant and interested voices. Personal histories and experiences, and colloquialisms and vernaculars should therefore be seen as a valid, if not vital, part of the debate as without them those voices who only know these ways of speaking, would effectively be silenced and equality and inclusivity would be illusory.

Habermas' ideas thus appear to provide an apposite starting point for the development of a civic theory of self-help groups: *prima facie*, these groups appear to occupy the spaces and be engaged in the activities with which Habermas' theory is concerned – they are generally located within the life-world but provide an institutional interface with more public spaces; they are understood to be sites primarily functioning through conversation and personal stories, even being described as 'narrative communities' (Rappaport, 1994); they claim to be grounded in democratic values, inclusivity and individual empowerment (Hatzidimitriadou, 2002); and they are seen as an example,



by opposite sides in the debate, of both concern with issues related to the common good and the good life, and an increasing tendency for inward-looking subjectivity (Giddens, 1991, 1998; Bauman, 1999).

Habermas' ideas can also provide a valuable tool with which to uncover threats to any civic function that these groups may possess. For example, hidden power disparities (Houston, 2002; Hayes and Houston, 2007) or co-optation and encroachment, disguised as participative democracy, by government agencies who, through processes such as service user consultations and policies such as the Expert Patient and Self Care agendas, are coming increasingly into contact with self-help type groups (Hodge, 2005; Karppinen *et al*, 2008).

### **Speaking Your Own Language: The Need for Independence**

For communicative rationality in the public sphere to thrive, maintaining independence from powerful structures such as the state is of crucial importance (McKee, 2005). Without this separation associations will struggle to develop according to their own logic or to create their own definition of needs (Habermas, 1989, 1996; Fraser cited in Houston, 2002) but will tend to succumb instead to the strategic aims of the system and be robbed of their ability to offer genuine or radical alternatives. For self-help groups this would mean the loss of their role as sites in which health and social care problems are reconceptualised by the people with direct experience of their effects (Munn-Giddings and McVicar, 2006).

Language, in particular the use of everyday, idiosyncratic speech, is often seen as a key means through which civic associations can resist threats to their independence and develop alternative ideas about the nature of and solutions to problems (Gardiner, 2004; Garrett, 2009). And this emphasis on the colloquial has tended to be put forward as a foil to Habermas' focus on rationality. However, as discussed, Habermas (1996, p. 360) placed a high value on the use of 'natural language ... general comprehensibility [and] everyday communicative practice' and even regarded dramatisation, through personal stories, as a valid form of civic discourse in its ability to bring broader political issues to life and increase their relevance among the general population. A central function of the public sphere is to counteract the system's hegemony through *unconstrained* communication, and clearly, if groups, especially among the disempowered, are made to use concepts and language that are alien to them, then their ability to express their needs and opinions in meaningful ways will indeed be constrained.

Self-help groups, in their guise of 'narrative communities' (Rappaport, 1994), are described as being grounded in their own 'unique language' systems and

philosophies (Williams, 1989; Katz, 2003) that come into being through storytelling and the sharing of life histories. And as such they provide a possible site for resistance to the hegemonic, technocratic language rules of dominant structures and the potential to articulate social problems or raise political questions in ways that animate and humanise the discourse of civil society – a role that Habermas (1996) saw as the key to meaningful grassroots input into political processes. Self-help groups, through their emphasis on de-stigmatisation and empowerment, have used these unique ways of talking about problems and needs to challenge negative labels imposed by dominant power structures within the system (Borkman and Munn-Giddings, 2008) and to effect positive changes to the language rules in operation in the public sphere. For example, Chamak (2008) describes how self-help groups in France have been instrumental in bringing acceptance of new models and definitions of autism that were proposed by the people with this condition themselves.

However, it cannot be presumed that all self-help groups will speak in this way and that their effects in civil society will necessarily be the same. Many groups evolve over time from small, local gatherings into large national organisations and as such will be more likely to engage in direct conversation with government agencies. When this happens, the voices of grassroots members can be drowned out by a professionalised leadership (Emerick, 1991; Buchanan and Walmsley, 2006; Chamak, 2008) whose parameters of negotiation will be limited to those defined by the state's agenda and pre-conceived outcomes. Ironically, these national organisations tend to have a greater likelihood of focusing on advocacy than smaller, local groups, and hence appear to be more engaged in political discourse and to possess that political dimension that is sometimes seen as lacking in small, local self-help groups (Brown *et al*, 2004). And yet, in terms of the independence and communicative rationality of their speech they may be making a less legitimate contribution to the public sphere than those groups who retain their own parameters for discussing the issues that affect them, and hence which may provide a more accurate reflection of the real needs of their constituents.

There is broad agreement in the literature that self-help groups are working increasingly closely with public health providers. The majority of commentators encourage these practices, believing they will lead to greater security, legitimacy and reach for self-help groups. However, little consideration has been given to how such relationships might affect self-help groups at the civic level (Stewart, 1990; Wilson, 1994; Adamsen and Rasmussen, 2001). For other writers, these closer relationships raise fears of co-optation and consequently a diminution of self-help groups' ability to present a radical challenge to the mainstream medical or political establishment (Emerick, 1991; Baldacchino and Hussein Rassool, 2006). For example, the provision of publicly funded training and



support for self-help groups is increasingly seen as desirable (Dunne and Fitzpatrick, 1999; Elsdon *et al*, 2000), with policies such as the Self Care agenda and Expert Patients Programme relying on the training of peers as 'experts' (DoH, 2006a). But this brings with it the possibility of professionalisation and the adoption of frames of reference epistemologically and conceptually grounded in technical expertise. It thus appears very different to self-help groups' idea of the peer role, which is to offer an alternative to the support and knowledge of experts (Munn-Giddings and McVicar, 2006), being grounded in actual experience rather than learned expertise and conveyed through everyday speech rather than technical jargon. The language employed in a newsletter published by a publicly funded self-help support agency illustrates how prescriptive, managerialist language and ideas could seep into the thinking and ethos of self-help groups who work extensively with mainstream agencies (OSHRC, 2005). The bulletin refers to the need for 'training', 'goals development' and 'evaluation' as well as 'frameworks' and 'blueprints' for groups' development, none of which sits comfortably with the spontaneity and anarchy (Katz, 2003) through which self-help groups are perceived to derive their 'unique' voice and values.

The heterogeneity that self-help groups can contribute to the discourse in the public sphere is also at risk from co-optation and use by the state to further its own strategic ends. This process is believed to have neutralised and emasculated the distinct conceptual frameworks of both the UK voluntary sector (Hedley and Davis-Smith, 1992) and the US psychiatric consumer movement (McLean, 1995) when they worked too closely with government agencies. Authors such as Stewart (1990) advocate closer links between self-help groups and professionals, for example, through self-help groups' input into professional training programmes. And while there may be advantages that come from broadening professionals' understanding of self-help philosophy and practice, it may also serve to encourage the appropriation of self-help language and values by mainstream structures, diminishing their impact as a genuine alternative. Similarly, the burgeoning of user involvement policies in the United Kingdom and the use of self-help groups and patients' groups to act as consultation partners (DoH, 2006b; Godin *et al*, 2007) can pose a threat to the vitality and spontaneity of self-help groups' dialogue. Consultation processes tend to work according to the parameters and language rules of the dominant party, and self-help groups have been observed to have had to reconceptualise the life stories that are their usual currency, into pre-defined issues (Munn-Giddings, 2003) that fit the prevailing policy agenda. The typical ways in which self-help groups discuss problems tend to be beyond the remit of consultations and hence excluded from the agenda for debate (Godin *et al*, 2007). At the same time though, incorporation of the idioms of self-help can be used to give an appearance of legitimacy and grassroots support to government policies.

Self-help groups have increasingly expressed a desire to spread the perceived benefits of what they do through the receipt of more regular referrals from mainstream health professionals, effectively moving closer to a service-provision-type role (Wilson, 1994). This development has been widely encouraged by commentators (Jacobs and Goodman, 1989; Katz, 2003). Again, though, little attention has been paid to the impact this might have on self-help groups' civic status. It has been observed that over recent years, as service delivery has become their main function, many voluntary sector organisations have become far more subjugated to the control and bound more closely to the strategic targets of the state, thus losing their independent voice in civil society (Fyfe and Milligan, 2003; Daly and Howell, 2006). Similarly, Dunne and Fitzpatrick's (1999) study of self-help groups revealed how it is those groups who conform to accepted bio-medical definitions of mental illness that tend to receive referrals from mainstream mental health agencies. Self-help groups may thus find themselves under pressure to conform to dominant labels and treatment models in order to gain the legitimacy that would result in their desired closer links with health services.

## What Constitutes a Civic Conversation?

Just as Habermas' emphasis on rationality has been the subject of dispute, so there has been extensive disagreement about what constitutes a valid topic for conversation in the public sphere. According to Habermas, public sphere speech should entail discussion about competing interpretations of the good life as well as universal moral issues such as freedom and justice, as opposed to the mere claims of niche interest groups engaged in making demands for themselves (Benhabib, 1992; McKee, 2005). His emphasis on universal issues of the common good has led critics to infer that Habermas would proscribe discussion of intimate or personal matters (Benhabib, 1992). However, Habermas (1996) acknowledges that modern politics is more interested in forms of life and identity than in the redistributive questions of the past and that 'the echo of private experiences' of 'diverse voices' (p. 364) are central to the development of ethical values. This means that questions about 'who we are, how we live' (Edwards, 2004), which frequently hinge on intimate matters but may exist within the context of broader moral principles such as justice, fairness and equality, would indeed be apposite subjects for civic debate.

The focus on 'how we live' as opposed to what can be claimed seems to be reflected in the purpose of self-help groups, the majority of which are not believed to see their role as making claims but rather as providing support and knowledge that will affect members' identity and ways of living (Ablon, 1981;



Wilson, 1994). Again, though, it should be noted that this will not be the case for all groups. Lieberman and Snowden (1999) describe how some groups evolve from small supportive or educational groups into groups whose primary purpose is advocacy, which may frequently involve making claims for increased welfare resources for group members. Similarly, national umbrella organisations are likely to have a greater role in this type of advocacy. However, making claims in this way will not automatically mean that groups are not engaging in valid civic discourse. The extent to which they do will depend on how far their claims have been arrived at through a process of communicative rationality.

Self-help groups have sometimes been seen as entirely inward-looking, focusing on their own narrow concerns rather than the needs of the broader community (Bauman, 1999; Borkman, 1999). And if this is the case, then their dialogue may have very little to contribute to public discourse. Certainly, the fact that the largest category of self-help groups addresses single, specific health conditions (Elsdon *et al*, 2000) coupled with smaller groups' tendency to focus inward on providing support to their members (Wilson, 1994) appears to buttress this view, and it has been noted that even when they become involved in political campaigns, group members can be reluctant to address broad issues, preferring to concentrate on individual stories (Radin, 2006). However, individual stories can provide illustrations of the application of universal principles. Indeed, this mediation between the personal and the political is an important role that associations should be playing within civil society in order to give more resonance to political issues and in order to give grassroots opinion an authentic means of expression that conveys ideas in ways that have direct recognisable relevance to peoples' lives (Habermas, 1996). Furthermore, self-help groups that begin by focusing on individual cases may gradually broaden their scope and gain understanding of wider issues. Wong and Chow (2005) describe how groups in their study that started with a very narrow viewpoint eventually became aware of the universal implications and problems of equitable resource allocation. In this way, self-help groups could provide a 'training ground' in which people are able to refine and expand the scope of their political discourse.

In recent years, health and medicine have increasingly come to be seen as a central component of citizenship in which patient status is directly linked to political activity through patients' role in decision-making processes (Zoller, 2005). Health is seen as salient to the most important and universally applicable problems of today, such as the balance between rights and responsibilities and questions of public governance (Landzelius, 2006). Similarly, some of the biggest current questions in ethics and philosophy regarding human agency and the value of human life have manifested as medical issues in the form of genetic screening, abortion time limits and assisted dying. It is therefore important that

these matters are the subject of unrestricted dialogue in the public sphere in order that the right questions can be raised at the political level. Self-help groups, through their focus on experience rather than technical expertise, can provide a unique form of knowledge that may be lacking in the discussions of politicians, scientists and jurists and hence can contribute to the articulation of more comprehensive questions. Indeed following Melucci's (1989) discussion of the impact of social movements, it may be that these types of question exemplify the limits of formal politics and can only be adequately articulated and resolved within the sphere of everyday life, in which self-help groups clearly operate. However, there is currently little empirical evidence about what, if any, role self-help groups have played in these debates. Even without this evidence though, it can be said that self-help groups provide forums that have the potential to enrich public knowledge and understanding about these issues.

According to Habermas, discussion within the public sphere should serve to increase the complexity of the debate (McKee, 2005). This is especially important in an age in which the mass media are seen as having 'dumbed down' political discourse (Goode, 2005). This is an area though, in which the effects of self-help groups appear to be somewhat equivocal. On the positive side, an important function of groups is to educate their members. They are often used as a forum to augment members' understanding of complex technological developments (Radin, 2006) and bureaucratic, welfare and judicial systems. Furthermore, many groups aim to educate the broader society (Katz, 2003; Goldstrom *et al*, 2006) about issues associated with their condition, or about broader matters connected with disability, addiction or mental health. Clearly, if this occurs, it will have a positive effect on the quality of public discourse, especially if groups are able to disseminate the information in comprehensible, everyday language.

The level of debate will also be raised by breaking down stigmatising and stereotypical images that allow complex arguments to be reduced to simplistic prejudice. Thus, as the central aim of many self-help groups is to deconstruct commonly held negative images (Ablon, 1981; Baldacchino and Hussein Rassool, 2006), these groups could again be said to increase the complexity of debate. On the other hand, however, the very desire to decrease stigmatisation can lead some groups to simplify political debate, for example, by stressing the biological causes of mental illness (Bond, 1992; Dickerson, 1998), and thereby negating the contribution of complex socio-political factors.

For Habermas (1989), the public sphere should provide a space where the interests of powerful authorities are problematised. Through their experiential epistemology and the development of a unique collective narrative (Rappaport, 1994), self-help groups can provide a means for undermining the monopolistic interpretations of the medical establishment and challenging the 'dominant



cultural codes' (Melucci, 1989, p. 75) that buttress existing social relationships. However, the contrary has also been observed, in that some self-help groups use their shared knowledge to reproduce rather than problematise dominant biomedical interpretations. Some groups have gone even further and played a key role in advancing processes of medicalisation (Rosencrance, 1985; Conrad and Schneider, 1992; Conrad, 2007). Kristian Barker (2002, 2008), in her work with fibromyalgia groups, has discussed the depoliticising effects of the groups' desire to assume medical labels that ultimately locates problems within the individual rather than the dominant power structures or broader society, and effectively removes issues from the sphere of public debate into the sole concern of technical experts. Similarly, Elsdon *et al* (2000) discuss how the acceptance of a medical model for behaviours such as addiction can diminish the possibility of broader discussion over the moral and ethical issues underlying those behaviours.

## Routes to Equality

Equality and an egalitarian structure are seen as crucial prerequisites for 'ideal speech' conditions within the public sphere (Habermas, 1989) and therefore civic associations would be expected to operate according to democratic and non-hierarchical principles. Any coercion or exploitation of power disparities would effectively amount to the displacement of communicative rationality with the strategic aims of the more powerful party.

It is frequently claimed that such democratic principles are also fundamental to self-help groups. Rootes and Aanes (1992) describe self-help groups as 'perfect democracies' in which domination can never occur. If this is so, then self-help groups would provide the ideal medium for communication within the public sphere. However, it appears to be an idealised view of these groups that, more realistically, are seen as possessing a whole spectrum of structures, from collegiate and democratic to individually led and authoritarian (Borkman, 1999). Indeed, the lack of a formal structure that is typical of small groups can itself make them more vulnerable to abuse of power (Habermas, 1996; Stolze, 2000). Furthermore, evidence suggests that group leaders tend to have a disproportionate share of power and organisational responsibility (Chaudhary *et al*, 2010). This means that the political learning that is claimed to take place in self-help groups (Elsdon *et al*, 2000) may not be benefitting the broader membership. And it is this political learning, of skills such as negotiation, organisation and navigating welfare or judicial systems, which is deemed vital to the civic impact that small groups, such as local self-help groups, can have within the current socio-political context (Marcello and Perrucci, 2000).

The implementation of policies such as the Expert Patient Programme can also increase the likelihood of hierarchy arising in self-help groups through the introduction of the concept of the trained, expert peer that could clearly come to be seen as having pre-eminence within the group.

Having said this, when talking about self-help groups it is important to remember that concepts derived from standard organisational theories will have limited applicability (Medvene, 1985). This is due to self-help groups' tendency towards informality, transience and lack of bureaucracy. Moreover, these groups frequently comprise people with serious, life-changing health conditions or with disabilities that confer feelings of stigma and isolation. Thus equality in self-help groups may not arise at the organisational level. Disempowerment caused by ill-health, trauma or social stigma may actually require a dominant or charismatic leader who undertakes most of the responsibility for directing and running the group. It is here that Habermas' ideas about 'collective identity' (1996) provide a very useful tool with which to assess the equality within self-help groups. It is through a common, authentic identity, derived through the experiences shared among peers within the group, that members are empowered to rebuild a more positive self-image that endows them with the self-worth to speak and be heard as equals (Ablon, 1981; Rappaport, 1994). Studying self-help groups from this perspective may thus highlight an important difference between formal, organisational and a more communicative type of equality.

Differentiating between these two types of equality by focusing on how far collective identity is maintained could account for the extent to which groups are perceived to represent their members' voices. This factor may help us to understand why some groups that grow into large, national organisations come to be seen as undemocratic and unrepresentative, excluding the views of grassroots members, whereas others do not. Interestingly, it is often the more politically radical groups, which claim to be grounded in egalitarian, emancipatory principles, that are more likely to evolve into national organisations (Emerick, 1991). But it may be the case that only some of these groups are providing the conditions to nurture a genuinely empowering and democratising collective identity. And again there may be lessons to be learned from small local groups, which are sometimes seen as lacking the political credentials to contribute at the civic level (Brown *et al*, 2004), but which in fact might possess high levels of communicative equality.

## Autonomy in the Lifeworld

For Habermas, effective communication in the public sphere is contingent upon a separation between the 'system' and 'lifeworld' (Houston, 2002). Even though



his later works acknowledge the need for mediation between these two spheres of life, maintaining a degree of independence in the lifeworld is still regarded as vital to the development of individuals' identities and their ability to act as self-directing agents. The moral agency acquired in the lifeworld allows individuals to articulate their own conception of the good life, rather than passively conforming to that defined by the state, and hence means they will have something original and valuable to contribute to the discourse within the public sphere. Habermas warned though that the system has a natural tendency to 'colonise' the lifeworld (Scambler, 1998), and that this colonisation will have the effect of increasing passive dependence on the state's services, thereby undermining this individuality and autonomy and thus impoverishing the public sphere.

In order to have a positive impact in the public sphere, self-help groups should be working to bolster relationships in the lifeworld among those people who may otherwise be more dependent on state welfare for support. The majority of the literature suggests that this is indeed a common outcome of participation in these groups. Self-help groups are seen as personal and 'intimate', providing friendship- and even family-type relationships to their members (Radin, 2006). It has even been suggested that they can act as a substitute for broken relationships caused by the fragmentation of society (Jacobs and Goodman, 1989; Adamsen and Rasmussen, 2001), a claim borne out by the fact that in the United States the divorced are the most frequent users of these groups (Lieberman and Snowden, 1999). Their members typically report effects such as increased empowerment and self-responsibility coupled with reduced dependence on professional services (Steinke, 2000; Katz, 2003). In addition to these direct effects in the lifeworld, this increase in personal empowerment is believed to have civic repercussions, such as heightening awareness of the broader social forces that impinge on people as individuals (McLean, 1995), increasing social capital and encouraging civic activism (Adamsen and Rasmussen, 2001; Hatzidimitriadou, 2002).

However, self-help groups can also have disempowering effects in the lifeworld. In particular, those groups that promote medicalisation, in positioning the individual as a passive object to be treated, and locating problems with diverse causes wholly within the individual body, can increase dependence on professional expertise and services and diminish the role of free will and human agency.

## Conclusions

The use of Habermasian theory in the analysis of self-help groups brings to the fore some of the most important criteria against which the democratic role of

self-help groups can be judged. In doing this, it provides the means by which to look beyond the presumptions that are frequently made about this aspect of self-help groups and allows us to develop a more nuanced understanding of their civic functions.

In trying to reach conclusions about self-help groups it is important to bear in mind their sheer scope and diversity, and therefore that generalisations will not be possible without more robust theory backed up by further empirical evidence. The aim of the article was to develop a line of enquiry for future research that can broaden our understanding of the numerous levels at which self-help groups work and the diverse ways that groups with particular evolutionary paths can make an impact in the public sphere.

The article suggests that Habermas' focus on communicative rationality makes his framework particularly suitable to the study of self-help groups, which themselves are seen to be grounded in narrative, discursive processes. Those characteristics and values that Habermas proposed as being most important to the public sphere provide salient ways of analysing the democratic effects of groups with different structures, aims and purposes. For example, groups involved extensively in consultation processes or who negotiate, through national leaders, directly with government, while appearing to be engaged in political conversations, may in fact sacrifice some of their communicative independence in participating in these dialogues. This raises the possibility that they become bound to the state's conceptual frameworks and strategic objectives rather than those of their members. It cannot therefore be presumed that large-scale, ostensibly radical, organisations that appear to be closer to the ideal of social movements, are acting in a more civic way than those smaller, local, typically self-help, groups that might appear to lack such a political dimension.

Similarly, groups that focus on service delivery or work very closely with professionals may be more likely to reproduce dominant ideologies and conform to the targets and aims of the state than those that do not.

The diverse organisational structures of self-help groups means that some are likely to be more democratic and egalitarian than others, with those that evolve into large national organisations sometimes developing extensive, potentially unrepresentative, hierarchies. However, the existence of an organisational hierarchy may not always result in an undemocratic group. The collective identity developed and assumed by group members may provide the means for a communicative equality, in which all voices are heard.

The different ways that self-help groups conceive and talk about problems will also affect the extent to which they can contribute to public discourse. Those that use their members' stories as a means of broaching broader principles or who see their role as increasing understanding of complex information, either among their members or within the society more broadly, will be likely to



have a positive impact on the quality of public debate, whereas those that locate problems in the individual, through promoting the medicalisation of behaviours such as addiction, tend to remove these issues from the public sphere and encourage dependency on experts, hence diminishing the role of personal autonomy and individual agency.

Habermas' model also helps us to identify the source and nature of tensions and threats to self-help groups' civic role. These tensions can arise through the ambiguous nature of some groups' objectives, for example, the simultaneous desire to maintain independence, but also to attain the legitimacy that would result in a greater number of referrals from public agencies. They can also occur in response to government policy and professional practice. For example, although service user consultations appear to provide the means for self-help groups to contribute to public dialogue, they may at the same time risk undermining these groups' linguistic and conceptual independence and heterogeneity. And the use of peer training programmes, as promoted by the Self Care agenda and Expert Patient Programme can increase the likelihood of self-help groups developing hierarchical structures and thus subjecting their discourse to power disparities that in turn can affect its rationality.

The application of Habermasian theory raises a number of questions for further research. It would be useful, for example, to consider the effects of the various structures that evolve within groups, such as the ways in which different leadership roles affect the political learning of members, the extent to which members see their views as being represented and the relationship these factors have to collective identity formation. Similarly, a comparison of the ways in which groups that follow different evolutionary paths talk about and articulate problems would help us to understand any differences between how large, national, and small, independent self-help groups define needs and problems. The health focus of the majority of self-help groups suggests a possible contribution to current ethico-political debates about issues such as assisted dying or genetic screening, however, as yet research has not addressed what role, if any, self-help groups have within such debates. Similarly, the extent to which the groups' concern with their members' welfare is grounded in universal principles such as justice or human rights could benefit from more detailed study. Likewise, at present, we know little about why some groups address stigmatisation in ways that emphasise biological causes and reinforce the medical model whereas others do not. Further understanding of such factors as the role of professionals within these groups or the extent to which members see their role as service providers may increase our understanding of these processes.

Locating self-help groups within a Habermasian, public sphere framework encourages us to consider and raise questions about self-help groups from beyond the narrow therapeutic perspective that has tended to predominate in

the literature and will allow us to better locate them within developing health citizenship theories. It provides the tools to question common presumptions and generalisations in order to identify which aspect of which type of group may be conducive to the efficacy of the public sphere, and the broader social forces such as policy and mainstream professional practice that may result in these features of self-help groups being diminished.

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## References

- Ablon, J. (1981) Dwarfism and social identity: Self help group participation. *Social Science & Medicine* 15B(1): 25–30.
- Adamsen, L. and Rasmussen, M. (2001) Sociological perspectives on self help groups: Reflections on conceptualisation and social processes. *Journal of Advanced Nursing* 35(6): 909–917.
- Alexander, J. (2006) *The Civil Sphere*. Oxford: Oxford University Press.
- Anheier, H. (2004) *Civil Society: Measurement, Evaluation, Policy*. London: Earthscan Publications.
- Baldacchino, A. and Hussein Rassool, G. (2006) The self help movement in the addiction field – Revisited. *Journal of Addictions Nursing* 17(1): 47–52.
- Barker, K. (2002) Self help literature and the making of an illness identity: The case of Fibromyalgia Syndrome (FMS). *Social Problems* 49(3): 279–300.
- Barker, K. (2008) Electronic support groups, patient-consumers, and medicalization: The case of contested illness. *Journal of Health and Social Behaviour* 49(1): 20–36.
- Bauman, Z. (1999) *In Search of Politics*. Cambridge: Polity Press.
- Ben-Ari, A. (1998) Understanding of and attitudes towards self help: Views from Palestinian and Israeli self help groups. *Journal of Social Service Research* 24(1–2): 131–148.
- Benhabib, S. (1992) Models of public space: Hannah Arendt, the liberal tradition and Jurgen Habermas. In: C. Calhoun (ed.) *Habermas and the Public Sphere*. Cambridge, MA: MIT Press.
- Bond, J. (1992) The medicalization of dementia. *Journal of Aging Studies* 6(4): 397–403.
- Borkman, T. (1999) *Understanding Self Help/Mutual Aid: Experiential Learning in the Commons*. New Jersey: Rutgers.
- Borkman, T. and Munn-Giddings, C. (2008) Self help groups challenge health care systems in the US and UK. In: S. Chambre and M. Goldner (eds.) *Patients, Consumers and Civil Society. Advances in Medical Sociology*, Vol. 10, London: Emerald, pp. 127–150.



- Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R. and Gasior Altman, R. (2004) Embodied health movements: New approaches to social movements in health. *Sociology of Health & Illness* 26(1): 50–80.
- Buchanan, I. and Walmsley, J. (2006) Self advocacy in historical perspective. *British Journal of Learning Disability* 34(3): 133–138.
- Cameron, D. (2010) Our Big Society Agenda. Speech. Liverpool, 19 July 2010, [www.conservatives.com/news/speeches/2010/07/David\\_Cameron\\_Our\\_Big\\_Society\\_Agenda.aspx](http://www.conservatives.com/news/speeches/2010/07/David_Cameron_Our_Big_Society_Agenda.aspx), accessed 31 August 2010.
- Chamak, B. (2008) Autism and social movements: French parents' associations and individual autistic organisations. *Sociology of Health & Illness* 30(1): 76–96.
- Chaudhary, S., Avis, M. and Munn-Giddings, C. (2010) The lifespan and life-cycle of self help groups: A retrospective study of groups in Nottingham, UK. *Health and Social Care in the Community* 18(4): 346–354.
- Conrad, P. (2007) *The Medicalization of Society*. Baltimore, MD: John Hopkins University Press.
- Conrad, P. and Schneider, J. (1992) *Deviance and Medicalization: From Badness to Sickness*. Philadelphia, PA: Temple University Press.
- Dahlgren, P. (2002) In search of the talkative public: Media, deliberative democracy and civic culture. *Javnost – The Public* 9(3): 5–26.
- Daly, S. and Howell, J. (2006) *For the Common Good: The Changing Role of Civil Society in UK and Ireland*, Democracy and Civil Society Series. London: Carnegie Trust.
- Damen, S., van Hove, E. and Mortelmans, D. (2000) Self help groups in Belgium: Their place in the care network. *Sociology of Health & Illness* 22(3): 331–348.
- Dickerson, F. (1998) Strategies that foster empowerment. *Cognitive and Behavioural Practice* 5(2): 255–275.
- DoH. (2006a) *Our Health, Our Care, Our Say – A New Direction for Community Services*. London: HMSO.
- DoH. (2006b) *A Stronger Local Voice: A Framework for Creating a Stronger Local Voice in the Development of Health and Social Care Services*. London: HMSO.
- Dunne, E. and Fitzpatrick, A. (1999) The views of professionals on the role of self help groups in the mental health area. *Irish Journal of Psychiatric Medicine* 16(3): 84–89.
- Edwards, G. (2004) Habermas and social movements: What's new? In: N. Crossley and J. Roberts (eds.) *After Habermas: New Perspectives on the Public Sphere*. Oxford: Blackwell.
- Elsdon, K., Reynolds, J. and Stewart, S. (2000) *Sharing Experience, Living and Learning: A Study of Self Help Groups*. London: Community Matters.
- Emerick, R. (1991) The politics of psychiatric self help: Political factions, interactional support and group longevity in a social movement. *Social Science & Medicine* 32(10): 1121–1128.
- Fyfe, N. and Milligan, C. (2003) Space, citizenship, and volunteerism: Critical reflections on the voluntary welfare sector in Glasgow. *Environment and Planning A* 35(11): 2069–2086.
- Gardiner, M. (2004) Wild publics and grotesque symposiums: Habermas and Bakhtin on dialogue, everyday life and the public sphere. In: N. Crossley and J. Roberts (eds.) *After Habermas: New Perspectives on the Public Sphere*. Oxford: Blackwell.
- Garrett, P. (2009) Questioning Habermasian social work: A note on some alternative theoretical resources. *British Journal of Social Work* 39(5): 867–883.
- Giddens, A. (1991) *Modernity and Self Identity: Self and Society in the Late Modern Age*. Stanford, CA: Stanford University Press.
- Giddens, A. (1998) *The Third Way: The Renewal of Social Democracy*. Cambridge: Polity Press.
- Godin, P., Davies, J., Heyman, B., Reynolds, L., Simpson, A. and Floyd, M. (2007) Opening communicative space: A Habermasian understanding of a user-led participatory research project. *The Journal of Forensic Psychiatry and Psychology* 18(4): 452–469.
- Goldstrom, I. *et al* (2006) National estimates for mental health mutual support groups, self help organizations, and consumer operated services. *Administration and policy in Mental Health Services Research* 33(1): 92–103.

- Goode, L. (2005) *Jurgen Habermas, Democracy and the Public Sphere*. London: Pluto Press.
- Graham, T. (2008) Needles in a haystack: A new approach for identifying and assessing political talk in non-political discussion forums *Javnost – The Public* 15(2): 17–36.
- Habermas, J. (1984) *The Theory of Communicative Action, Vol. 1: Reason and the Rationalisation of Society*. Boston, MA: Beacon.
- Habermas, J. (1989) *The Structural Transformation of the Public Sphere: An Inquiry into a Category of Bourgeois Society*. Cambridge: Polity Press.
- Habermas, J. (1996) *Between Facts and Norms: Contributions to a Discourse Theory of Law and Democracy*. Cambridge, MA: MIT press.
- Hatzidimitriadou, E. (2002) Political ideology, helping mechanisms and empowerment of mental health self help/mutual aid groups. *Journal of Community and Applied Psychology* 12(4): 271–285.
- Hayes, D. and Houston, S. (2007) ‘Lifeworld’, ‘System’, and family group conferences: Habermas’ contribution to discourse in child protection. *British Journal of Social Work* 37(6): 987–1006.
- Hedley, R. and Davis-Smith, J. (1992) *Volunteering and Society: Principles and Practice*. London: NCVO.
- Hodge, S. (2005) Competence, identity and intersubjectivity: Applying Habermas’s theory of communicative action to service user involvement in mental health policy making. *Social Theory & Health* 3(3): 165–182.
- Houston, S. (2002) Re-thinking a systemic approach to child welfare: A critical response to the framework for the assessment of children in need and their families. *European Journal of Social Work* 5(3): 301–312.
- Jacobs, M. and Goodman, G. (1989) Psychology and self help groups: Predictions on a partnership. *American Psychologist* 44(3): 536–545.
- Karlsson, M., Jeppsson, G.E. and Hansson, J. (2002) Self help groups in the welfare state: Treatment program or voluntary action? *Non-profit Management and Leadership* 13(2): 155–167.
- Karppinen, K., Hallvard, M. and Svensson, J. (2008) Habermas, Mouffe and political communication: A case for theoretical eclecticism. *Javnost – The Public* 15(3): 5–22.
- Katz, A. (2003) Fellowship, helping and healing: The re-emergence of self help groups. *International Journal of Self Help and Self Care* 2(1): 21–33.
- Kelleher, D. (2001) New social movements in the health domain. In: G. Scambler (ed.) *Habermas, Critical Theory and Health*. London: Routledge.
- Landes, J. (1995) The public and the private sphere: A feminist reconsideration. In: J. Meehan (ed.) *Feminists Read Habermas: Gendering the Subject of Discourse*. London: Routledge.
- Landzelius, K. (2006) Patient organization movements and new metamorphoses in health. *Social Science & Medicine* 62(3): 529–537.
- Lieberman, M. and Snowden, L. (1999) Problems in assessing prevalence and membership characteristics of self help group participants. *Journal of Applied Behavioural Science* 29(2): 166–180.
- Marcello, M. and Perucci, R. (2000) Small groups and civic engagement – All about me? *The Communitarian Network* 10(3), [http://www.gwu.edu/~ccps/rcp/rcq\\_smallgroups.html](http://www.gwu.edu/~ccps/rcp/rcq_smallgroups.html), accessed 21 September 2012.
- McKee, A. (2005) *The Public Sphere: An Introduction*. Cambridge: Cambridge University Press.
- McLean, A. (1995) Empowerment and the psychiatric consumer/ex-patient movement in the United States: Contradictions, crisis and change. *Social Science & Medicine* 40(8): 1053–1071.
- Medvene, L. (1985) An organisational theory of self help groups. *Social Policy* 15(3): 35–37.
- Melucci, A. (1989) *Nomads of the Present*. Philadelphia, PA: Temple University Press.
- Munn-Giddings, C. (2003) *Mutuality and Movement: An Exploration of the Relationship of Self Help/ Mutual Aid to Social Policy*. Loughborough, UK: Loughborough University.
- Munn-Giddings, C. and McVicar, A. (2006) Self help groups as mutual support: What do carers value? *Health and Social Care in the Community* 15(1): 26–34.
- Nash, V. and Paxton, W. (2002) *Any Volunteers for the Good Society*. London: IPPR.



- New Economics Foundation. (2010) *Ten Big Questions about the Big Society and Ten Ways to Make the Best of It*. London: NEF.
- Office of the Deputy Prime Minister. (2005) *New Localism – Citizen Engagement, Neighbourhoods and Public Services*. London: HMSO.
- Ontario Health Promotion Bulletin 399. (2005) *Frameworks and Skills for Keeping Self Help Networks on Track*. Ontario: Ontario Self Help Resource Centre.
- Radin, P. (2006) 'To me, it's my life': Medical communication, trust and activism in cyberspace. *Social Science & Medicine* 62(3): 591–601.
- Rappaport, J. (1994) Narrative studies, personal stories, and identity transformation in the mutual help context. In: T. Powell (ed.) *Understanding the Self help Organisation*. California: Sage.
- Rootes, L. and Aanes, D. (1992) A conceptual framework for understanding self help groups. *Hospital and Community Psychiatry* 43(4): 379–381.
- Rosencrance, J. (1985) Compulsive gambling and the medicalization of deviance. *Social Problems* 32(3): 275–284.
- Scambler, G. (ed.) (1987) Habermas and the power of medical expertise. In: *Sociological Theory and Medical Sociology*. London: Tavistock.
- Scambler, G. (1998) *Modernity, Medicine and Health: Medical Sociology Towards 2000*. Florence, KY: Routledge.
- Scambler, G. and Kelleher, D. (2006) New social and health movements: Issues of representation and change. *Critical Public Health* 16(3): 219–231.
- Steinke, B. (2000) Rehabilitation initiatives by disability self help groups: A comparative study. *International Social Security Review* 53(1): 83–107.
- Stewart, M. (1990) Professional interface with mutual aid self help groups: A review. *Social Science & Medicine* 31(10): 1143–1158.
- Stolze, T. (2000) A displaced transition: Habermas on the public sphere. In: M. Hill and W. Montag (eds.) *Masses, Classes and the Public Sphere*. London: Verso.
- Whelan, R. (1999) *Involuntary Action: How Voluntary is the 'Voluntary' Sector?*. London: IEA.
- Williams, F. (2004) Care, values and support in local self help groups. *Social Policy and Society* 3(4): 431–438.
- Williams, G. (1989) Hope for the humblest? The role of self help in chronic illness: The case of ankylosing spondylitis. *Sociology of Health & Illness* 11(2): 135–159.
- Williams, G. and Popay, J. (2001) Lay health knowledge and the concept of the lifeworld. In: G. Scambler (ed.) *Habermas, Critical Theory and Health*. London: Routledge.
- Wilson, J. (1994) *Self Help Groups and Professionals*. York: Joseph Rowntree Foundation. Social Care Research 60.
- Wong, D.K.P. and Chow, S.F. (2005) Beyond clinical trials and narratives: A participatory action research with cancer patient self help groups. *Patient Education and Counselling* 60(2): 201–205.
- Zoller, H. (2005) Health activism: Communication theory and action for social change. *Communication Theory* 15(4): 341–364.



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