What do self-help/mutual aid groups contribute to creating and sustaining civil society?

In this cross-cultural Panel we set out to explore and contrast the ways in which key stakeholders (government, professionals and the general public) in our respective countries understand, support or constrain a common form of grassroots activity that forms part of the underbelly of civil society– Self-help/mutual aid groups (SH/MAGs).

SH/MAGs are a form of activity between peers who share a similar health, economic or social condition/situation, who meet together (face-to-face or online) to share their experiences and coping strategies of living with a specific health condition or social situation. Self-help/mutual aid groups cover every conceivable health and social situation, for example, cancer, mental health, diabetes, single parenthood, gay rights. Groups may also follow the 12-step tradition prevalent in the addictions or be entirely organic grassroots groups that do not have a prescribed process or structure to adhere to.

The term SH/MA is deliberate to emphasise an important distinguishing feature of activity because it is based on reciprocity known as the 'helper-therapy principle' (Reissman 1965). This means that those involved in self-help are helped and enabled themselves through the process of helping others (Hastie 2000).

Whilst their form may be culturally shaped across and between countries these groups share some common principles:

¬ They are led by and for peers in the same situation

¬ Members both give and receive support

¬ They build a distinctive knowledge base based on direct experience of a situation or condition

SH/MAGs therefore are a very particular type of collective citizen participation, occupying a space between the private and public spheres (Habermas, 1984, 1996). The type of collective knowledge built in groups, over time, can be both challenging and/or complentary to lay and professional understandings of their condition or situation.

The Panel will co-present 3 linked papers each of which helps us understand in more detail how the specific form and role of SH/MAGS contributes to strengthening civil society.

Paper 1: Civil participation and self-help groups: A German and UK case study
Led by Prof. Jürgen Matzat

This paper will explore what the collective knowledge built in SH/MAGs offer that is distinctive to an 'individual' citizen's view. Centring primarily on Germany as a case study the paper will explore how policy makers recognised the 'experiential knowledge' built in SH/MAGs. For example, in Germany 'patient' participation is enabled explicitly via the network of self-help/mutual aid groups that exist and a network of self-help centres. As a comparator we will also the situation in the UK where well developed public and patient involvement mechanism exist in all aspects of a citizen's education and care but where until relatively recently the emphasis has been on individual client's experience at the expense of understanding collective knowledge built over time in groups. The paper will explore dominant understandings and policy initiatives in both countries to assess how far the concept of "collective experiential knowledge" is understood, incorporated or distorted by policy makers and what the wider consequences are for the impact of citizen knowledge on democratic institutions.

Paper 2: What are the relationships of self-help/mutual aid groups to professionals?
Led by Prof. Tomofumi Oka

This paper will address the range of ways in which self-help/mutual aid groups and 'professionals' relate to one another in five countries: UK, German, US, Mexico and Japan. Beginning with the premise that the welfare context is critical to understanding the type of relationships that develop (for example contrasting countries with high level welfare states to those that are heavily privatised) we give a brief outline of the history of professional involvement with groups in each country and then pose/explore a number of questions ranging from: why governments fail to distinguish between the two and/or legitimise professionally led groups over professionally led support groups; The roles professionals may have to groups and whether SH/MAGs can change professional perspectives to recognise and value their experiential knowledge.

Paper 3: What do self-help/mutual aid groups offer to citizens themselves?

Led by Prof. Thomasina Borkman and Prof. Carol Munn-Giddings

In this paper we take a closer look at the processes involved in SH/MAGs and the types of benefits that arise for citizens that take part in them. The first part of the paper will be based on the secondary analysis of data from US study on 12-step groups and a UK study on 'grassroots'' groups comparing and contrasting the ways in which these groups 'talk' and exchange stories. Unusually, we draw on a theoretical framework from a physicist Bohm (1986, 1997) to explain the empirical commonalities we observed such as suspension of judgement, active listening, inquiry and reflection. We conclude with a summary of known benefits attributed to the citizens who take part in groups and consider their implications for broader social and cultural capital in democracies.

Civil participation and self-help groups: A German and UK case study

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This paper will explore what the collective knowledge built in SH/MAGs offer that is distinctive to an 'individual' citizen's view. Centring primarily on Germany with the UK as a comparator the paper will explore how policy makers recognise the 'experiential knowledge' built in SH/MAGs. The paper will begin by describing how patient participation was established in Germany`s health system. Germany is a social welfare state. It`s health system is regarded as one of the best and one of the most expensive in the world. The main financial source is contributions from employees` income (approximately 15%) collected and administered by statutory not for profit health insurance funds under public law.
Self-help groups, mainly related to health matters, have developed and spread widely in Germany since the 1970s. As in many other countries key to their definition is that are: "voluntary…whose activities are directed toward coping in common with illness, psychological or social problems, …The goals of the self-help groups focus on theirs members, and not on outsiders; in that respect they differ from other forms of citizens` action groups. Self-help groups are not led by professional helpers, although some consult experts now and again on particular questions."
The number of self- help groups in Germany is estimated to approximately 100.000 (given a population of 80 million). About half of these groups are local chapters of larger self-help organisations, active mostly on national level. Self-help organisations have formal membership including subscribed declarations and regular fees. They provide information on the respective disease, medical condition, or social situation and act as a lobby standing for the interests of those affected (not only their members) and theirs carers. Approximately 300 professionally run local self-help centres promote and support self-help groups and provide information and advice for all citizens interested in self-help groups.
Since the beginning of the century the statutory health insurance schemes, covering 90% of the populations on a non-profit basis, are obliged by law to fund self-help groups, self-help organisations, and self-help centres (clearinghouses) currently over 40 million Euro (54 million $). Since 2004 "patient representatives", their vast majority coming from the self-help scene are involved by law in decision making bodies of the German health system. The most important being the Federal Joint Committee, which decides on which diagnostic and therapeutic procedures will be compensated by the health insurance under public law.
As a comparator in the second part of the paper we will also explore the situation in the UK where a similarly strong statutory welfare system has existed which mandates all aspects of public and patient involvement spanning citizen's education and care. Although sophisticated these mechanisms have, until relatively recently, emphasised the individual patient or citizen experience at the expense of understanding collective knowledge built over time in SH/MA groups. The paper will explore dominant understandings and policy initiatives in both countries to assess how far the concept of "collective experiential knowledge" is understood, incorporated or distorted by policy makers and what the wider consequences are for the impact of citizen knowledge on democratic institutions.

What are the relationships between self-help/mutual aid groups and professionals? Case studies from five countries

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This paper explores the relationships between self-help/mutual aid groups (SH/MA groups) and professionals in five countries: the US, the UK, Germany, Mexico and Japan, while considering the cultural and political differences among these countries. The following three questions arise from this exploration.

First, in countries where welfare and/or professional services support socially disadvantaged people, is the role of the SH/MA groups diminishing or do they continue to be seen as a viable alternative? If SH/MA groups and professionals complement each other, and professionals amplify the content of their services, are SH/MA groups to be considered as secondary, or do they perform functions that are unavailable from professional services?

Second, when communities that are traditionally based on geographical adjacency and blood or business relations deteriorate in developed countries, people have fewer opportunities to develop the social skills needed to maintain communities. Do contemporary citizens in developed countries then fail to recognize SH/MA groups as a new type of community? Or do they regard SH/MA group meetings as something similar to professional-led group therapy meetings? If the answer is yes to these questions, SH/MA group meetings would not be seen as part of community life, but rather a temporary gathering that could be easily replaced by a professional-led support group.

Third, as the number of professionals increases in a society, they tend to aggressively explore new frontiers and claim that many life issues can be cured or solved by their treatments. Issues including depression, grief, neurosis and social phobia become pathologized and medicalized – to be treated only by trained professionals. Huge economies based around pharmaceutical companies and government-subsidized non-profit organizations arise. Can SH/MA groups grow independently from professional services in these areas? Or are they forced to partly or wholly take professional perspectives in place of their “liberating meaning perspectives,” which are designed to empower the socially stigmatized? Or can SH/MA groups change professional perspectives to recognize and value their experiential knowledge?

The case studies presented in this paper give very interesting answers to the above questions because the five countries involved have different financial and cultural contexts in relation to SH/MA groups. First, the countries had different percentages of social expenditure to GDP in 2010: Germany (27.1%), the UK (23.8%), Japan (22.3%), the US (19.8%), and Mexico (8.0%) (OECD, 2013). This helps us to understand how SH/MA groups can work as complementary to or independently from government social support. Complementary SH/MA groups might be more likely to merge with professional-led groups.

Second, people in the five countries showed very different pro-social behaviour indices in 2010: the US (60), the UK (57), Germany (44), Mexico (34) and Japan (26) (OECD, 2011). Also, different percentages of people are active members in charitable/humanitarian organizations: the US (29%), the UK (21%), Mexico (14%), Eastern and Western Germany (3% and 5% respectively), and Japan (2%), and different percentages of people confide in charitable/humanitarian organizations: 75% in the UK, 68% in Western Germany, 65% in Mexico, 64% in the US, 62% in Eastern Germany, and 32% in Japan (Inglehart et al., 2010). These figures may indicate whether SH/MA groups tend to be more altruistic or offer member-only benefits in each country. Less altruistic SH/MA groups might be similar to professional-led support groups.

Third, people in countries trust experts differently. “Having experts make decisions” is considered good by 74% of people in Mexico, 68% in Eastern Germany, 54% in Japan, 49% in the UK, and Western Germany and 44% in the US (Inglehart et al., 2010). The more people believe in experts, the more likely SH/MA groups are to be susceptible to professional authority rather than “experiential authority” (Borkman, 1999). This paper presents full details of each case study.

What do self-help/mutual aid groups offer to citizens themselves?

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In this paper we consider key social processes involved in self-help/mutual aid groups and briefly summarize the types of benefits for citizens that take part in them. First, “sharing”, a specialized form of talking and communication appears to be a major social technology of self-help/mutual aid and is found in groups with contrasting styles of interaction, health & social issues, and organizations. A comparative secondary analysis of talk in 12 step groups in the US and in a grassroots group in the UK (Borkman & Munn-Giddings 2010) is reviewed; the research found major similarities in the characteristics of “sharing” despite cultural, organizational and subject matter differences. The theoretical framework of “dialogue” proposed by the physicist Bohm (1987, 1996) and further developed by others (Dixon 1996) that focuses on active listening, suspension of judgment, inquiry, and reflection fits the data; Bohn saw dialogue as a way of developing shared meaning and contrasted it with discussion which is used to analyze and separate phenomena. Sharing may be the key social technology by which self-help/mutual aid groups exchange information and support, assist participants in problem solving their individual issues, collectively develop experiential knowledge which in some cases includes liberating meaning perspectives, and create cohesive social relations and a sense of community.

The paper concludes with a summary of known benefits to self-help/mutual aid participants and considers their implications for broader social and cultural capital in democracies. Self-helpers for some health & social issues belong to alternative “normalized” communities instead of being limited to a patient role in the health care system. Some self-help/mutual aid groups have created “liberated meaning perspectives” that empower their members and provide alternative to more restrictive and stigmatized professionally-defined ones. Self-helpers with chronic conditions often have improved symptoms, reduced distress, and more health-promoting behaviors and they may experience reduced rates of re-hospitalization compared to non-users. Self-helpers make better patients when they seek medical care utilizing the practitioners time and collaborating more effectively with the medical professional. Self-help/mutual aid groups are sources of effective primary “treatment” of smoking cessation, recovery from alcohol or drug abuse. While self-help/mutual aid appeals to diverse ages, genders, backgrounds, life situations, racial/ethnic and cultural groups and settings in most industrialized countries, the caveat is that self-help/mutual aid attracts only a small minority of people with a given issue that are theoretically eligible to participate in a group.

Self-help/mutual aid groups contribute to society with their alternative “meaning perspectives” to prevailing professional frameworks. Self-helpers are “lay” volunteers working to help themselves and to help others, to critique professional and public services, and to contribute the “Patient” perspective to health and social services and policy; unfortunately little research has been done to document their impact on policy or services.