# 4 How Social Governance, Health Care, and Civil Society Shape Self-Help/Mutual Aid and Peer Support in Europe

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The purpose of this section is to draw on selected European literature to provide a wider lens(es) on this article as a whole. We consider two core themes raised by this literature review and revisit them from the perspective of European-based research, highlighting the relationship of SHGs and SHOs to broader social, political, and cultural contexts.

After many years of cross-country collaboration, Borkman and Munn-Giddings noted in 2008 that, despite the many and important similarities that their research illuminated about the shared characteristics, processes, and benefits of SHGs and SHOs to self-helpers, there were important differences and subtle nuances between their countries (United States/United Kingdom) to how these organizations operated. This led them to state that researchers or analysts who write in universalistic terms, and who draw on bodies of knowledge as if the country were irrelevant, create context-free assertions that often do not hold up to scrutiny. The differences relate to the disciplines of the researchers involved in research and the dominant framings and methodologies they employ, which are further reflective of the sociopolitical, welfare, and cultural systems they inhabit.

The English-speaking European research base is not a silo. Particularly in the United Kingdom, it draws on the North American tradition and literature that shares similar interests and—indeed—findings on the motivation of self-helpers and the benefits they accrue for individual self-helpers and self-help groups. Researchers are drawn from a variety of fields, including community development, social psychology, social work, sociology, and social policy. However, reflective of its interdisciplinary base, the European tradition tends to be psychosocial in nature, with emphasis accorded to the impact and democratic role of SHGs and SHOs and their relationship to their wider communities. The latter point might refer to the characteristics of a particular region and its service provision or how the groups’ activities support their wider community of interest, such as in mental health or disabilities. For example, Munn-Giddings and McVicar (2007), in addition to exploring the benefits for carers who join SHGs, also look at the social capital built in these groups, which can have broader benefits to the communities they reside in; and Chaudhary, Avis, and Munn-Giddings (2013) conducted research that modeled SHGs’ democratizing effects in the public sphere.

The literature reviewed for this section has been selectively chosen to reflect different regions of Europe (Northern, Southern, Eastern, and Western) along with different welfare systems, with the aim of providing insights into core issues in the field. We acknowledge the inherent limitations of using only articles published in English, and do not claim that the literature is fully representative of the region, nor of SHGs and SHOs in the country context. Instead, our intention is to problematize the dominant knowledge base in a field that, quite naturally, has been shaped by research in North America, where the majority of researchers into self-help have traditionally been based.

We have organized this section around two main areas of inquiry. The first examines the relationship of self-help groups to professionals and government; the second explores shifting forms and understandings of self-help/mutual aid. Five in-depth vignettes of six selected countries across Europe are discussed to highlight the difference that political and welfare landscapes make in the issues raised. To provide context for the overall discussion, we present the key welfare features and sociopolitical landscapes of the selected countries for this chapter in Table 6.

Capturing and representing diverse welfare states using a typology of regimes is fraught with complexity and nuance (Kasza, 2002). Since Esping-Andersen’s (1990) seminal work that differentiated welfare states into three ideal regimes (Liberal, Conservative, and Social Democratic), numerous alternative typologies have been developed (Bambra, 2007). While we acknowledge the challenges inherent in classifying diverse welfare systems across and within various countries according to a well-ordered typology, we maintain that it provides a useful context to understanding the national and local welfare systems that can shape self-help initiatives. With this in mind, Richardson et al.’s (2019; informed by Bambra & Eikemo, 2008) framework of European welfare regimes is applied, as it recognizes Eastern European countries as presenting a distinctive regime type.

Briefly, Richardson et al.’s (2019) typology consists of five distinct welfare regimes. First, the Bismarckian regime (Austria, Germany, Netherlands, France, Switzerland, Belgium) is influenced by the early social welfare policies of Otto von Bismarck, which is typified by benefits being related to earnings that are administered by employers and geared toward maintaining existing social hierarchies. The role of the family in providing care is emphasized within such regimes. Mediterranean regimes (Spain, Italy, Greece) are typified by a fragmented system of welfare provision consisting of diverse income-maintenance schemes with different levels of provision. Reliance on the family and voluntary sector for services is also prominent. In contrast, Social Democratic regimes (Sweden, Denmark, Norway) are characterized by the ideals of universalism in service provision, along with a commitment to full employment and income protection. States that are interventionist and that promote social equality through a redistributive social security system typify these regimes. The former Communist countries of Central and Eastern Europe inform the Post-Communist regimes (e.g., Czech Republic, Poland, Slovenia, Estonia) and are characterized by the collapse of universalist Communist welfare state and social and economic disruption. Marketization and decentralization has occurred in recent years, following the example of Liberal welfare regimes. State provision of welfare services is minimal. Finally, Liberal state provision of welfare (United Kingdom) is founded on the principles of providing a minimal safety net, with modest levels of social protection and strict entitlement criteria. Recipients are usually means-tested, and private saving and welfare schemes are encouraged through tax incentives.

Table 6

Comparison of Welfare Regimes and Sociopolitical Landscapes in Europe and the United States

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| --- | --- | --- | --- | --- | --- | --- |
| Region | Country | Welfare regime | Nature of health care system | Universal health coverage? | Patient involvement | Specific self-health policy? |
| Northern Europe | Norway | Social Democratic | National health insurance (tax-funded) | Yes | High | Yes |
| England, United Kingdom | Liberal | National health insurance (tax-funded) and optional private insurance | Yes | High | No |
| Southern Europe | Greece | Mediterranean | National health insurance (tax-funded) and optional private insurance | Partial | Low | No |
| Eastern Europe | Croatia and Slovakia | Post-Communist | National health insurance (tax-funded) and optional private insurance | Yes | Medium | No |
| Western Europe | Germany | Bismarckian | National health insurance (tax-funded) and optional private insurance | Yes | High | Yes |
| United States | United States | Liberal | Private health insurance and discrete types of national-level health insurance | No | Medium | No |

*Note*: Welfare regime classification system from “Country-Level Welfare-State Measures and Change in Wellbeing Following Work Exit in Early Old Age: Evidence From 16 European Countries,” in Richardson et al. (2019). CC BY 4.0.

## 4.1 Relationship of Self-Help Groups to Professionals and Government

A recurring theme in the research on SHGs relates to their autonomy (or otherwise) from the state, as well as from the practitioners whose professions define their focal issue and deliver services accordingly. While this is important, Dill and Coury (2008) suggest that this theme should be moved away from a contextless examination of the relationship of professionals to groups to refocus on an examination that foregrounds the political and social contexts within which these relationships occur. When we look to Europe, there is not a homogeneous picture, as can be seen from the various types of welfare regimes and policies in just a few selected countries. However, it is this rich diversity that helps us to shed further light on this common area of research concern. In particular we illuminate how, compared to North America, the stronger statutory welfare provision, particularly in Western and Northern Europe (Boyce et al., 2014; Lundström & Wijkström, 1997; Matzat, 2006), leads to closer and sometimes intertwined relationships between professionals and SHGs; in addition, we show how the historical relationships between citizens and state services in less well-resourced regions in Central and Southern Europe (Pavolini & Spina, 2015; Menediatou et al., 2018; Dill & Coury, 2008) can mean that SHGs neither are, nor wish to be, independent of state support.

“Professionals” are not a homogeneous group, and the “self-help supporter” (Oka & Borkman, 2011) is a useful concept. Oka and Borkman define the “self-help supporter” as a professional, official, or anyone who is not a peer member of a self-help group, but who “respects the autonomy and integrity of the group and works as the members wish” (2011, p. 16). Reflecting on the ways in which professionals are involved with groups further raises issues related to SHGs’ power and authority, which Borkman (1999a) crystallized in terms of two important questions: Who, with what authority, can initiate, reconstitute, or disband a group? And who, with what authority, can change the group’s rules of operation (e.g., who decides on the agenda and *meaning perspective*)? While few studies explicitly adopt either the concept of a self-help supporter or pose the latter questions, we have used both as a guide to consider the types of relationships that are illuminated in three vignettes of countries representing different welfare regimes.

### 4.1.1 Vignette 1: England, United Kingdom

England is characterized by a liberal society with a universal health care system that covers all citizens and that is free at the point of delivery. However, the system has become increasingly nuanced in the last decade or so, with aspects of the health system moving into not-for-profit companies and a rising private sector—the latter for those who can afford it. England does not have a self-help-specific policy, but since the 1980s there have been increasingly well-developed policies, structures, and systems in health, social care, and education for involving people with lived experience—those who are varyingly referred to as “citizens,” “service users,” or “patients”—in the design, delivery, and evaluation of service provision. Accompanying legislation (Department of Health, 2001, 2005, 2007; Department of Health & National Health Service [NHS], 2006, 2009; Health Education England, 2017) has mandated this; for example, the largest health grant-making body, the National Institute for Health Research (NIHR), will not consider research proposals unless experts by lived experience have been involved at the design stage. In addition, people with lived experience are involved in the design of nursing and social work curricula, as well as the recruitment, delivery, and assessment of new vocational graduates (see, for example, Holttum et al., 2011; E. Levin, 2004).

In keeping with the individualistic model of care prevalent in UK society, the accompanying initiatives tend to be aimed at involving individuals rather than working through collectives like SHGs, where the knowledge a participant brings has, in Borkman’s terms, been developed over time through reflection and challenge within a collective community of peers. This is in distinct contrast to Germany (see Subsection 4.1.2) and Norway, which both have self-help-specific policies, including the use of state funds allocated to self-help activities. In terms of infrastructure in England, while there are numerous service user organizations, there is only one key organization—Self Help UK (SHUK), founded in 1970—whose specific mission is the support and development of SHGs across the country. Based in the middle of the country, it is in a region that has a strong mutual aid history from the industrial period onwards, and its initial focus was on the Nottinghamshire region—as reflected in its original name, Self Help Nottingham, which was changed in the 2000s to signify its national reach.

Despite the United Kingdom’s lack of a specific policy about SHGs, there are rafts of legislation about service user involvement in health and social care. From the 2000s onwards, the potential benefits of peer support (particularly in mental health) began to be acknowledged at governmental level. This policy interest partly came in response to pressure from service user movements, but it was also in the context of hard-line austerity policies. In addition, “peer support” has largely focused on time-limited 1:1 time schemes in statutory or charitable services, run by newly accredited peer workers, with little attention to distinguishing or acknowledging the potential of long-term use of face-to-face SHGs to support members’ well-being. However, the heightened interest in peer support saw many services encouraging their workers to support self-help more generally, although without guidance on how to do so.

It is within this context that a national study led by SHUK in collaboration with Anglia Ruskin University and Nottingham University, called ESTEEM (2010–2013), was initiated, specifically exploring the ways in which practitioners could best support SHGs without damaging their member-led status and mutual aid ethos. This built on research carried out in 1995 by Judy Wilson, the then-Director of SHUK, that identified the “two worlds” that professional services and SHGs work occupy in relation to values, structures, and sources of knowledge. The study stemmed from SHUK’s concern that, in the changing policy landscape in the 2000s, which was giving more prominence to peer support and SHGs, practitioners were being asked to support SHGs without necessarily understanding their organization and ethos. The study was therefore specifically designed to explore with SHGs and practitioners the most effective roles practitioners could adopt to support the development and maintenance of SHGs, while respecting the autonomy and integrity of groups to produce training and resources to be used by SHUK. The study methodology was participatory action research; thus, in addition to incorporating the views of twenty groups and their members and twenty-six practitioners, there was also an advisory group representing self-helpers, practitioners, commissioners and policy makers, and all of the participants were offered opportunities to shape various stages of the research process. Data was collected via semistructured interviews, focus groups, and reflective feedback sessions with practitioners and SHGs (see Munn-Giddings, McVicar, et al., 2016). The majority of professionals who took part in the study were identified by SHGs as already supportive to their groups and could therefore, by dint of recruitment method, be seen as champions or “self-help supporters.”

Overall the study highlighted the complexities and nuances that characterize the relationships of practitioners to self-helpers. A complex picture emerged from this research that illuminated a wider range of roles and activities that practitioners contributed to group development than was previously understood. Practitioner support spanned organizational development (such as printing leaflets and co-organizing events and venues to meet); nurturing group members and processes (such as mentoring, signposting leadership training, and highlighting their group and achievements); and providing information (such as arranging for speakers and inviting them to relevant decision-making events in services). Both the self-helpers and practitioners highlighted the reciprocal nature of this relationship and the mutual learning that ensued. However, the relationship was not without its challenges, and a concern expressed by practitioners was finding the right balance between “hands-on” support and avoiding dependency. There was agreement on both sides that, for practitioners and groups to find constructive ways to work together, building trust was essential to defining boundaries to the practitioners’ role and recognizing the value and benefits of peer-led support.

Practitioners discussed the challenges of working with SHGs in three main areas: their working relationships with groups, changing support needs over time, and inclusive and participatory practice. Echoing Wilson’s earlier research (1995b), they noted that their ways of working were often in tension with groups in terms of understanding the informal nature of groups, such as the timing of meetings organized around members’ circumstances. They also had tensions with other colleagues who were antagonistic toward or felt threatened by groups. The informal nature of groups raised ambiguities about confidentiality and sharing information, suggesting that the solution was to be very clear from the outset about what they could offer to groups and the limits to their relationship. They were conflicted over whether to intervene to assist groups with, for example, recruiting a more diverse base and whether to help a group close or sustain. All of the practitioners emphasized the importance of group autonomy and providing clarity about the limits of their role to avoid dependency; a minority of practitioners felt that professional help with facilitation could be important when group members were perceived as vulnerable.

Overall the study found a spectrum of autonomy across different groups but also within the same groups at different times of their evolution. New groups often needed more practitioner support than established groups, but there was a fundamental difference between groups established by peers and those established in the first instance by professionals: Those established by peers developed a stronger sense of mutual ownership from the outset, whereas member ownership was sometimes unclear or underdeveloped when the group was professionally instigated. However, this simple distinction fell apart in cases where practitioners set up groups with a clear mission from the outset for the group to transition to being member-led and provided transitional facilitation for that to occur, such as by building members’ skills in chairing, enabling members to lead the discussion, and so forth. The research led to flexible and fluid “roles” being defined to enable practitioners to help groups think about the needs of SHGs at different stages of their development; these roles have been used extensively by SHUK in training to over 1,000 practitioners in the United Kingdom and by SHGs to help them think through their support needs.

### 4.1.2 Vignette 2: Germany

In Germany, “self-help supporters,” in the form of progressive academics and maverick professionals, can be seen to be intertwined in the growth and formal recognition of SHGs from the outset. Germany is arguably a unique case example, as not only is there a self-help-specific policy in the country, but Germany has invested at a federal level in a countrywide system of self-help advice centers that are statutorily funded from health insurance monies (Borkman & Munn-Giddings, 2020; Matzat, 2001), and financial support for self-help is an obligation of Germany’s statutory health insurance.

While other countries like the United Kingdom have widespread policies for involving people with experiential knowledge, they lack understanding of the importance of what Borkman (1976a) terms *collective experiential knowledge*. This form of knowledge has been reflected on over time with peers and therefore is not “raw” and unprocessed, but mature and reflective of the wider experience in groups. Germany explicitly recognizes and values this collective knowledge base, and has built it into the intricate and extensive systems of support that have developed since the 1960s.

Jürgen Matzat (personal communication, 2010), director of the National Self-Help Support Center in Germany, notes that the growth of single-issue SHGs in Germany can be traced to the AA groups founded by American GIs in 1953. However, he contextualizes the broader growth of SHGs and what he terms “collectives without professional leadership” not only within the global social movements in the 1960s, but also within the particular cultural context of student rebellions in Germany that highlighted a perceived silence in society about the Nazi period.

Self-help supporters in the shape of physicians who were disaffected by the medical system actively encouraged the self-help movement in the 1970s and 1980s by offering practical support to SHGs through providing them with rooms, facilities, and medical information. This was bolstered by influential texts by Moeller, a psychoanalyst and a group therapist, who drew on his observations of the growth of SHGs in the United States and who promoted the importance and benefits of SHGs (Moeller, 1978). He initiated the first ever study of SHGs as part of a larger-scale reform of psychiatric care, looking at the benefits of professional support that would not undermine ownership of groups (a similar focus to the ESTEEM project in the United Kingdom described in Subsection 4.1.1). This study involved Matzat, who was a young psychologist at the time. The resulting report (Daum, Matzat, & Moeller, 1984) was published by the state and supported by the Federal Ministry of Health and Social Affairs—a symbolic show of support to the public for SHGs. It spawned follow-up action research projects that specifically explored what kind of guidance or support professionals could offer while preserving the autonomy of groups. The tone and ethos of relationships between professionals and SHGs therefore came into being at a very early stage with a clear commitment to and respect for member-led groups.

Also, in this era, a German working group for the support of SHGs—an informal circle of people interested in supporting SHGs—was established. It mostly consisted of the research teams above, professionals working in universities, psychotherapists in private practice or hospitals, and staff of various counseling centres. A minority of the group were members of SHGs, while some were both. Discussions were wide-ranging but included questioning whether professionals should cooperate with SHGs or just leave them alone. Matzat calls this a “reaction formation” (2006, p. 284) against their apprehension toward their own professional dominance. This activity spawned the first generation of self-help clearinghouses by people wanting to promote self-help in their respective institutions.

Further international support was garnered from the World Health Organization (WHO) regional office in Copenhagen, which published a book in 1983 edited by Stephen Hatch (England) and Ilona Kickbusch (Germany) titled *Self-help and health in Europe*. This brought together an international task force recommending that professionally run self-help clearinghouses be established at national, regional, and local levels. An accompanying umbrella organization was established in Dubrovnik, Croatia, bringing together hundreds of universities across the world and organizing courses for scholars. As part of their program “Health for All,” a course on self-help was held annually. Scholars from Europe and throughout the world met to exchange ideas and experiences. These initiatives were used as leverage by German self-help activists.

Matzat says these phases led to the acceptance and legitimization of SHGs. However, he notes that there was a mixed reaction amongst professional groups. While many were accepting and supportive of self-help, others found it a threat to their profession, believing that the groups might become rivals and deplete their client base and income. The latter included the president of the German Doctors Association and some psychotherapists.

Matzat and colleagues elaborated the role of the self-help clearinghouse, which acted as an intermediary between SHGs and professional services and, interestingly, also offered information on possibilities outside self-help that were provided by professional services. This suggests that SHGs were being conceptualized as complementary rather than an alternative or challenge to professional services. The full history is described in detail by Matzat (2006). Threaded through his article is the notion that staff who are self-help supporters belong to two cultures at the same time: they belong at heart to the self-help movement but to their respective professional communities by their training.

By 1987 the federal government actually asked how best to support SHGs. The self-help working group recommended pilot projects at the federal level to be evaluated. These evaluations showed that in areas with clearinghouses, the numbers of groups rise significantly, as do the numbers of people participating (see Matzat, 2006, p. 287). The studies also reinforced the importance of clearinghouses—the latter seen not only as a source of support for SHGs, but also professionals wishing to collaborate with them. Perhaps a more controversial but nonetheless consensus finding was that clearinghouses should be run by professionals. The controversy, of course, rested upon the danger that professionals could distort the clearinghouses and remodel them as professional services.

Since the early days, a number of additional policy changes have further embedded SHGs into the fabric of welfare supports. For example, in 1999, a law was introduced requiring that statutory health funds support self-help, which was then written into the code of social law. In 2000, money from Germany’s nonprofit statutory health insurance funds under public law became available. Further, when statutory health insurance funds spend their money on self-help, they must consult representatives from one of four core associations for self-help.

Self-help supporters not only acted as champions of SHGs, but also were the more powerful voice in formal and public forums as a proxy for SHGs themselves. While the SHG organizational model being member-led and autonomous makes the groups able to define their own meaning systems, there is always the risk that not having a direct voice constrains more radical agendas. In 2004, SHG members’ participation was enhanced by their inclusion on the “Joint Committee,” which was responsible for all decisions regarding the German health system. These patient representatives had three rights: (1) to speak as they wish on matters that concerned them (rather than just being asked for their opinion), (2) to put topics on the agenda, and (3) to be present when voting takes place. Matzat noted that although the final clause placed limits on their power, their presence made a big difference. Further observations suggest that only self-helpers with knowledge about and who were at ease with formal bureaucratic services were likely to come forward. Important caveats, however, were that the law requires that the SHG representatives be well-informed people drawn from SHGs or professional organizations (such as clearinghouses) working in the field of self-help support. The idea is that people bring not only their individual experience or knowledge but also the experience of their respective organization in its totality. The second qualification is that they have experience in committee work and negotiations; therefore, they need to have a broad understanding of more than their own issue and have some knowledge about the health system, including its financial limitations. They also need to understand the language of evidence-based medicine. In short, expectations of patient representatives are high.

Related initiatives, such as the introduction of “Self-Help Friendliness and Patient-Centered Care” in Germany in 2004, reflect close working relationships between professionals and SHGs in the health services. Nickel, Trojan, and Kofahl (2017) suggest that, despite its success, the notion that health care institutions can “grant” friendliness to SHGs connotes paternalism rather than partnership.

While there may be risks associated with this close and mutually embedded relationship between SHGs and self-help supporters, these initiatives were turning points—or, as Matzat puts it, a symbolic and actual recognition of self-help from both the German state and the Medical Association. Since the early 2000s, every general practitioner in the country has had access to the addresses of SHGs and clearinghouses. The embedding of SHGs into the fabric of health systems continues to this day, with Matzat stating in 2020 (personal communication, April 17, 2020) that, by decision of national parliament, the financial support provided by statutory health insurance schemes under public law for (local) SHGs, (nationwide) SHOs, and the more than 300 self-help clearinghouses all over the country has risen to €1.15 per capita per year. And “patient representatives” are now mainly from self-help organizations and have seats in an ever growing number of committees, from local and regional levels to the national level (cf., the Gemeinsamer Bundesausschuss, https://www.g-ba.de/english/).

### 4.1.3 Vignette 3: Slovakia and Croatia

In literature from European countries that face severe economic difficulties and have less of a state system to support them, the relationships of SHGs to both the state and professionals also tend to be interdependent, but take a different form from well-resourced countries. A particularly interesting example is provided by Dill and Coury (2008) reporting on a rare study based in Slovakia and Croatia (both previously part of the former Yugoslavia), which focused on SHGs and their relationship to professionals and the state. The study took place as the countries were transitioning from Communism to Western-style democracies. Their study foregrounds how relations between professionals and self-help groups can also depend on social and material relations that go well beyond the domains of systems of care (Dill & Coury, 2008, p. 248).

After the war in what was then Yugoslavia in the early 1990s, both governmental and service systems were moving in the direction of promoting more voluntary sector expansion with a market economy that fueled nongovernmental organization (NGO) expansion. The system of self-management that had organized all public institutions was effectively abolished, and newly independent countries created centralized health and social care arrangements, but with restrictions of entitlement and introduction of copayments and secondary insurance. An important context is that Yugoslavia had a long history of support and infrastructure for the voluntary sector, including mutual aid, that predated the collapse of Communism (e.g., user councils paralleling those of providers, which included SHGs). As previously noted, Dubrovnik (then part of Yugoslavia) was the center of a European umbrella supported by WHO to run an annual course on self-help for scholars and practitioners.

Dill and Coury’s (2008) study took place over a seven-year period (2001–2007) and included a range of SHGs; through observations, interviews, and document analysis, they focused on groups’ relationships with the health or social care professionals and the state. Groups ranged from those over three decades old, established during the Communist period, to newer groups addressing contemporary social issues. Key findings illuminated how, in transitional societies, both SHGs and the wider third sector were dependent on the state, with few existing independently from formal service organizations.

Relationships with professionals were, however, neither subservient nor independent; instead, groups act as corollaries and educators to the professional realm. Both older and newer groups showed mixed patterns of connections with professionals; some were initiated by professionals, but many operated under member leadership. Critically, in relation to the two questions posed by Borkman, they maintained their control over their structures and agendas. Older groups tended to be more professionally controlled than newer ones, but there were exceptions in each category, and relationships were more complex than they initially appeared. As Dill and Coury state, on the surface many groups looked like “support groups” by some definitions, but this lens would obscure the extent of member autonomy and their own goals (2008, p. 252). For their study, Dill and Coury adopted Gidron and Chesler’s 1994 definition devised for international analysis: “the recruitment and mobilization of peers in an informal and non-hierarchical setting, and the sharing of their common experiences” (Gidron & Chesler, 1994, p. 3).

As part of her international research, Borkman (2015) visited Croatia in 2012 and undertook a small-scale reflective study with both members and professionals in a “Club of Treated Alcoholics.” These aftercare programs were government-based treatment programs. To acquire NGO status these clubs needed to be legally registered. Borkman found that although there was a requirement to have a professional facilitator (a social worker in this instance), the members—who comprised not only the persons with an addiction but also their family members—select, hire, and contract the professional who will be their “expert help.” The power ostensibly rests with the group, as they can decide whether to rehire that professional or otherwise. The social work facilitator considered her role to be nondirective; rather, she saw herself as “enhancing conversation, providing reflective ways for members to think about what they were doing” (Borkman, 2015, p. 27). However, she also noted that some facilitators might be more directive than others. Seasoned members (abstinent for five years or more) provided support to their peers, which resonates with Golik-Gruber et al.’s (2001) study of the same type of clubs, where peers abstinent for ten or more years received education to become co-therapists.

The vignette above illustrates that groups neither wished nor wanted to be independent of state support, and embraced their relationships with professionals who appeared to be “self-help supporters.” In countries facing adverse economic situations, this closer relationship can be seen as critical to third-sector growth. Despite the constraints on economic and political resources, Dill and Coury noted the opportunities that the transitioning countries provided for both older and newer groups to develop and assert their own meaning systems. Their closer relationships to professionals and the state meant that, although these groups were more likely to assert a social change agenda than those in North America or Northern or Western Europe, their agenda was less radical and aimed more at social inclusion and ways of working within societal and professional systems to promote better services, greater access to public goods, and increased social acceptance. The findings are also illustrative of the potential and limits of citizen involvement in new nongovernmental sectors and how these relationships depend on social and material relations beyond the realm of health care systems—underscoring yet again the importance of social and political contexts.

### 4.1.4 Subsection Summary

These vignettes illustrate the layered and complex relationships between professionals and SHGs. They show the potential benefits to both when professionals are sensitive to and respectful of SHGs and behave, in Oka and Borkman’s (2011) terms, as “self-help supporters.” If we look again at that definition, however, as someone who “respects the autonomy and integrity of the group and acts as the group wishes,” the waters are a little muddier.

In each of the vignettes there are examples of the ways in which professionals can undertake practical roles to support the groups. The English example shows that relationships are likely to vary over time and according to SHG needs. It also highlighted the tensions regarding boundaries that confront practitioners, particularly in relation to inclusive (or otherwise) practices. Germany is a unique example of having SHGs embedded in the development of health policy and practices; nonetheless, it provides examples where self-help supporters’ voices have been proxies for groups themselves. Croatia and Slovakia serve as examples of how we need to look beyond the surface of policies—there, SHGs appear to need professional legitimization, yet they remain in charge of finding their own “self-help supporters” with the authority to “fire” professionals who do not meet their needs.

The question of a group’s autonomy, however, is tricky. In each of the vignettes the members have the right to decide their own agenda and operate in ways that provide the grounds for defining their own *meaning perspectives*; yet, all have a level of interdependence with professionals. Dill and Coury (2008, p. 250) suggest the importance of bracketing the question of group autonomy when working in settings where there has been little independence of action beyond structures provided by or condoned by the state. They argue that SHGs in the transitional countries differ in critical ways from those in the United States and in Northern and Western Europe because of the level of urgency in their need for building collaborative links with professionals to survive. As SHGs in these settings seek to transform not merely individual but also collective and public identities, they should be understood as building civil society through a symbolic as well as a material remaking of public space. This observation resonates with the broader European psychosocial research tradition that situates SHGs within their wider systems and structures.

Regardless of this, how embedded SHGs should be in the structures of a state and its related health and social care systems is a moot point. Both Germany and England highlight in different ways how governmental policies have helped to embed experiential “voices” in the ways health and social care services are developed and delivered, with only Germany honoring the particular role of SHGs and, thus, collective experiential knowledge. Being “embedded” in a state system might offer opportunities for more power and authority, but might simultaneously create potential opportunities for co-option into the system, reducing the ability of self-help activists to challenge rather than complement biomedical frameworks and ensure the equity of their relationships.

## 4.2 Shifting Forms and Understandings of Self-Help/Mutual Aid

The focus of this second guiding inquiry is to explore, from a European perspective, the shifting forms and understandings of self-help/mutual aid. To demonstrate this inquiry, vignettes from Greece and Norway are presented. While these two countries have distinctly different welfare regimes, this examination highlights how the growth and development of self-help/mutual aid initiatives in Greece and Norway has been respectively influenced by austerity measures and government regulation, leading to a shift and distortion in the understandings of self-help/mutual aid principles.

### 4.2.1 Vignette 4: Norway

In Richardson et al.’s (2019) typology of European welfare regimes, Norway is classified as Social Democratic, where social rights are grounded in citizenship regardless of status differentials (van Kersbergen, 2016). In this model, typical of the Nordic countries (Sweden, Denmark, Finland, Norway, and Iceland), the welfare state is tax-financed, yet social provision and access to good health and social care services remain open to all, irrespective of personal finances (Munn-Giddings & Stokken, 2012). Hence, the management of illness and health are recognized not only as an individual issue, but also the collective responsibility of public and welfare policy (Hedlund, Landstad, & Tritter, 2019).

Since the 1960s, Norwegian health and welfare policy has emphasized the principle “help-to-self-help” and user involvement, meaning that an individual is expected to support themselves and manage everyday life as best they can, underpinned by the support of welfare measures and policies (Hedlund & Landstad, 2012). These ideals were further developed and formalized in 2004 with the adoption of a National Plan for Self-Help by the Norwegian Directorate of Health and Social Affairs (DHSA). The premise of the national plan was to increase self-help in Norway, thereby strengthening an individual’s ability and possibility to take part in their own change process (Madsen, 2015).

In 2006, the National Nodal Point for Self-Help (NPSH) was established as the expert center to organize and deliver the implementation of self-organized self-help nationally. In 2009, the enterprise was made a permanent item on the Norwegian state budget, where NOK 16.5 million was allocated in 2015 for operational purposes (Madsen, 2015). The resourcing and embedding of self-help within Norway’s health and social care policy agenda appears, at first review, a great triumph and an enviable position, particularly in comparison to countries like the United Kingdom and United States where there is no specific self-help policy or funding. However, the grounding principles of how self-help is supported and delivered in Norway have faced criticism, most notably by Hedlund, Landstad, and Tritter (2019, p. 35), who argue that self-help is now more about “helping the state and the health system than helping those who wish to help themselves.”

In their review of publicly accessible online documents related to SHGs in Norway, Hedlund, Landstad, and Tritter (2019) highlight that specific rules are expected to be followed by members of an SHG, such as the signing of nondisclosure agreements and a discouragement of group members meeting or greeting each other outside group meetings. The motivation for these conditions, which are stipulated by the NPSH, relates to the framing of self-help as a process where individuals are responsible for improving their life situation. In this framework of understanding, self-help is deemed a form of personal work, which has the potential to be undermined by the building of close friendships and intimacy, and thus the latter are actively discouraged by the NPSH. Failure to conform to these principles means that such groups are not acknowledged as part of the program coordinated and resourced by the NPSH. Hedlund, Landstad, and Tritter (2019) conclude that the model of self-help promoted by NPSH remains an alternative to biomedicine, but one that is characterized by regulation and discipline. Moreover, it would appear that the “help-to-self-help” principle that informs Norwegian welfare state policy is reflected in the National Plan for Self-Help, as self-help remains narrowly defined as “do-it-by-yourself”—to the exclusion of mutual aid.

This shifting emphasis on professionalization and individualism within self-help/mutual aid in Norway is interwoven with the ideals of neoliberalism, which, since the early 1980s, in response to a worldwide financial crisis, have shown greater influence and growth. The intellectual and contextual origins of neoliberalism continue to generate much debate and disagreement. Turner (2011) identifies four core characteristics of the ideology. They emphasize the market as the most efficient mechanism for generating wealth and as allocating resources through a spontaneous and self-regulating order, assigning a minimal role to the state and thus, by default, maximizing individual liberty. The welfare state is thus assigned a residual role that promotes independence, personal responsibility, and self-reliance, underpinned by a constitutional framework of government and politics that entails a separation of powers whose prime purpose is to guarantee liberty, enforce contracts, and maintain the rule of law. Lastly, prominence is given to the promotion and protection of private property, underpinned by the associated rights pertaining to the lawful acquisition of wealth, inheritance, and independence from the state. This, Turner (2011) concludes, provides the basis of a market economy based on private enterprise and ownership of the means of production.

While the United States and United Kingdom were the first to adopt this ideology in the 1980s, other countries soon followed. Initially Norway was slow and cautious in adopting neoliberal market strategies, which was due, van Riemsdijk (2010) argues, to its social democratic tradition where there has traditionally been a strong consensus among its citizens that the state should take care of them in times of illness and disability and in their old age. The author continues that an emphasis in Norway on the promotion of the common good and egalitarian values, solidarity, and high standards for social welfare placed it at odds with competition-based strategies. Nonetheless, high public expenditures have encouraged the state to implement neoliberal reforms and cost-cutting measures, such as privatization and contracting-out services (Dovemark et al., 2018; van Riemsdijk, 2010). The impact of this shift within Norway and among neoliberal states more broadly has been an ever-increasing responsibility on the individual to realize processes of increased control and health improvements (Hedlund & Landstad, 2012). These abstract ideas and ideals have impacted self-help/mutual aid in Norway, as we see an emphasis on and privileging of individual responsibility over collective, reciprocal processes.

The top-down, disciplined nature of how SHGs are formally organized in Norway is at odds with their original grassroots self-help/mutual aid principles of informality and anti-bureaucratic, democratic spaces (Borkman, 1999a; L. F. Kurtz, 1997; Wann, 1995). Most notably, the NPSH model fails to acknowledge the unique features of interdependence between self-responsibility and mutuality that occurs in SHGs (Borkman, 1999a; Hatzidimitriadou, 2002; Munn-Giddings & Borkman, 2005). The giving and receiving of mutual aid is a key characteristic of SHGs, where the individual and the reciprocal mutual aid process are equally emphasized and their interconnection is highlighted (Borkman, 1999a; Boyce, 2017). Yet, at a bureaucratic, governmental level, these founding characteristics are being ignored in Norway. Instead, the rules and disciplining of SHGs that are enforced by the NPSH appear to be shifting the emphasis to one where there is a maximum priority given to self-help, with the individual taking responsibility for their health and well-being, and minimum importance given to mutual aid—especially seen in the closely guarded peer-support interactions.

An emphasis on regulation and discipline mean that SHGs, under the umbrella of the NPSH in Norway, are more akin to professionally based support groups. The distortion of self-help/mutual aid by the NPSH raises questions around the types of SHGs that are being promoted in Norway and what space, if any, there is for groups that choose not to follow these governmental regulations. Ultimately, the narrative being endorsed by the NPSH is leading to a new hybrid style of SHGs, where the control and regulation of the group does not lie with group members, but with external, governmental forces.

The next vignette explores the distortion of self-help/mutual aid principles further by looking at the recent social and economic changes that have occurred in Greece, which have created a space for and expanded self-help/mutual aid initiatives. Nonetheless, despite this initial expansion, the country faces similar shifts and distortions in understandings of self-help/mutual aid principles.

### 4.2.2 Vignette 5: Greece

Mediterranean welfare regimes, found in Spain, Portugal, Italy, and Greece, are traditionally typified by the prominent role of the family in developing strategies to protect and augment the welfare of family members in response to inefficient welfare-state institutions (Mari-Klose & Moreno-Fuentes, 2013). Self-help/mutual aid groups and activities have traditionally not been common in these countries (Corradini, 2018; Sotiris, 2009) due to the underdevelopment of an organized civil society (Tzifakis, Petropoulos, & Huliaras, 2017). However, following the economic crisis, which began in 2008, there has been a notable shift and development in self-help/mutual aid initiatives and activities, particularly within Greece.

Before the economic crisis in Greece, civil society was largely underdeveloped and was instead dominated by political parties that operated factions in major associations, such as labor and student unions (Sotiropoulous, 2014). Historically familial bonds that restricted the trusting of non-relative members also contributed to the underdevelopment of Greece’s civil society (Tzifakis, Petropoulos, & Huliaras, 2017). Access to public health care and pensions was unequal and depended upon a person’s occupational insurance scheme, although most of the population was covered in one way or another. Following the economic crisis, the government’s response in Greece was to drastically cut social expenditure, resulting in the retreat of the state from the social protection of all. As a consequence, Greek citizens became unable to rely on their personal income, the receding welfare state, or on Greece’s traditionally weak voluntary sector. After the crisis, uninsured persons lost access to public hospital care, and pension earners saw their income from pensions fall below the poverty line. Unemployed and self-employed people who had stopped paying health insurance to their occupation-based social security funds also lost access to public health care (Sotiropoulos & Bourikos, 2014).

In response to the crisis, many social solidarity groups and initiatives emerged in an informal and spontaneous way. Voluntary organizations active in social solidarity started catering not only to socially excluded groups, but also to newly impoverished Greek citizens seeking social services and basic consumer goods. At the same time, informal social networks and self-help groups emerged and became active in the free exchange of goods and services, such as food and clothes (Sotiropoulos & Bourikos, 2014). Volunteers and members of these new initiatives were drawn locally from different socioeconomic backgrounds, with the united aim of materially and emotionally supporting each other. The development of these groups and initiatives opened up spaces for civil society protest and activism, which Sotiropoulos (2014) argues has led to a revitalization of civil society in Greece and the enrichment of democratic life. As the government rolled back the welfare state, citizens stepped in to occupy the newly available space. They distrusted the state because it remained governed by the same elites whom voters considered responsible for the derailment of the Greek economy. Civic activists wanted to distance themselves from the state and to help people affected by the crisis. In response, Sotiropoulos and Bourikos (2014) report that informal social solidarity groups and self-help groups developed all over Greece, and were active in the exchange and distribution of goods, services, and support.

Distinctly, these groups offered a more critical view of the state and sought alternative forms of social organization. Sotiropoulos and Bourikos (2014) conclude that the economic crisis functioned as a catalyst that revitalized Greek civil society, particularly with regard to social solidarity, and allowed new, informal types of civic-minded activity to emerge. Ultimately, this has led to the self-awareness of citizens being raised with regard to both their rights and their ability to mutually support one another in difficult times (Sotiropoulos, 2014). While the economic crisis may have opened up Greece’s civil society, it is questionable how much this momentum of self-help/mutual aid initiatives has been maintained as, for example, SHGs continue to remain rare and underdeveloped in Greece (Menediatou et al., 2018). Furthermore, from the literature available, there appears to be shifts and distortion around how the principles of self-help/mutual aid are being applied and developed.

In 2014–2016 the Citizens Against Depression project was delivered in six Cyclades islands and five selected areas in and around Athens, in partnership with mental health professionals and people with lived experienced of depression, to provide psycho-education on and access to SHGs for coping with depression (Menediatou et al., 2018). The main purpose of the project was to train mental health service users in organizing SHGs for depression. To do this, 105 potential facilitators of SHGs received training primarily from mental health professionals on the mechanics of running an SHG. At the time, five new SHGs were formed following this training program. However, a major frustration raised by those who attended the training program was the lack of involvement from people with personal experiences of depression and experience as SHG facilitators in the delivery of the program. This is perhaps not altogether surprising, as patient involvement in Greece remains relatively low and limited, although initiatives like Citizens Against Depression are indicative of a gradual shift to the reforming of health care services through the participation of patients and service users.

Nonetheless, the approach adopted by the Citizens Against Depressionproject illustrates how the principles of self-help/mutual aid can be adopted while distorted from their original meaning and motivations. The concern is that unless direct, lived experience remains central within self-help/mutual aid initiatives, the strategies for coping and experiential knowledge base will be de-emphasized and skewed toward more professional frameworks. Going forward, the Citizens Against Depression project aims to develop a strategic plan for Greece’s national mental health care policy to replicate and support the setting up of SHGs across the country, based on the rationale that they offer a low-cost response to the socioeconomic constraints Greece continues to face (Menediatou et al., 2018). An emphasis on the supposed cost-effective benefits of SHGs has been shown to be a narrow and misguided interpretation (Munn-Giddings, Boyce, et al., 2011). The learning that often takes place in such groups means that members often become better informed about the resources and services that are available to them, and, as a result, may initially increase health and social care costs (Munn-Giddings, Boyce, et al., 2011). More than this, which the Citizens Against Depression project ignores and distorts, is that SHGs developed not as a replacement for services, but as a complement or alternative to existing services (Boyce, 2016; Munn-Giddings & McVicar, 2007).

### 4.2.3 Subsection Summary

A review of current self-help/mutual aid approaches and initiatives in Norway and Greece demonstrates that they share similarities in their interpretation and framing of self-help/mutual aid. The catalysts for the development of self-help/mutual aid initiatives in these two countries are not the same; nonetheless, both these countries distort the grounding principles of self-help/mutual to fit their own social and political agendas. It is this fluid distortion that serves as a cautionary tale for the future development and sustainability of self-help/mutual aid, within Europe and beyond.

## 4.3 Conclusions: What Can We Learn?

Drawing from the vignettes, we can conclude that SHGs are a vibrant part of the welfare landscape, with or without state support or policies. As Dill and Coury (2008) observed, the structures and functions of SHGs may differ because of different social contexts and policy legacies, but their contributions to civil society might be similar in terms of providing arenas for contesting social problems, redefining identities, and contributing to the overall expansion of voluntary associations. The vignettes, taken together, have illuminated that single-issue groups are one form of mutual aid that are part of a much bigger mutual aid and welfare landscape. Mutual aid activities of all kinds both contribute to and are shaped by their wider sociopolitical circumstances in any given historical period. This is entirely in keeping with the perspective of the European psychosocial research tradition, which moves the reader’s gaze from the internal workings of the SHG or SHO (micro) to the wider organizational (meso) and societal/global (macro) contexts in which they operate.

The different examples have challenged the simple binary where SHGs are either an alternative or a complement to state or professional support. Rather they offer something quite unique to their members in terms of egalitarian social relations between peers, and their relationships to professionals and the state are nuanced and complex. The history of a country and its formal welfare regime sometimes obscures the type of relationship they may have. Indeed, the examples presented demonstrate the crucial importance of considering a country’s social, political, and welfare contexts in relation to its development and delivery of self-help/mutual aid initiatives. Failure to do so has the potential to generalize at the expense of nuance and understanding. For example, on one hand, it may be surprising that a country with Germany’s history has such an intertwined, strong, respectful, and supportive relationship between professionals and SHGs; on the other hand, this is not surprising given that “professionals” were part of the radical movements in the 1960 and 1970s that spawned the growth of single-issue groups there. Norway, with its social democratic government, is surprising. Nordic countries, which have been noted for their strong sense of social responsibility and for putting citizens before economic development, appear to have created a very bureaucratic model of support for SHGs—one that goes as far as to define the way in which “autonomous” groups can behave in order to be recognized and supported by the formal structures in place. Having a self-help-specific policy or otherwise does not therefore necessarily indicate an open mind to the ways in which SHGs form, operate, and provide for their members.

Excepting Greece, all of the countries have patient involvement policies to varying degrees. However, they differ as to whether their commitment to experiential knowledge distinguishes between individual and collective experiential knowledge. Germany has the clearest and longest commitment to embedding SHGs in their health systems and valuing the distinctive knowledge base they bring. There is also evidence of this recognition in Croatia and Slovakia, albeit without the resources to enable the level of support provided by a rich and mature democracy like Germany. England has for many decades shown increasing commitment to the views and perspectives of service users and carers in its health and social provisions, but rarely shows an understanding of the difference between the “raw” or idiosyncratic experience that a service user might bring and the experience of a seasoned SHG member.

None of the countries featured have been exempt from the creep of neoliberalism into their state policies and processes. In countries that have particularly borne the brunt of economic recessions and disruptions, such as Greece, Croatia, Slovakia we can see that economic austerity leads to renewed energy in mutual aid activities in different forms, including health and social care single-issue groups. However, it is likely to lead to an ambiguous governmental response that might view “self-help” as a panacea to state spending—a do-it-yourself culture that elevates citizen action as a way of legitimizing reductions in state spending.

We write this section from England during a global pandemic that comes with the predicted threat of the biggest global economic recession since the early 1700s. Already we have seen a massive upsurge in community mutual aid, both in practice and in media coverage. This renewed interest in mutual aid holds opportunities for it to be recognized as a vibrant part of a democratic society, but also the danger that it could be co-opted by neoliberalism to underpin cuts in state funding.

# 5 Conclusions

When embarking upon the journey of conducting this review over a year ago, I had no idea that it would be so revealing. An early and fortuitous decision was made to approach the review somewhat chronologically, beginning with the 1970s and 1980s when research on SHGs and SHOs first exploded in North America. Because of that decision, I saw that the story had to be told first as the history of what had happened in the first twenty to thirty years (see Section 2), followed by what research focused on for the next twenty years around the time of the institutionalization of SHGs (see Section 3). In the early 1990s, as globalization increased its pace, North American social science research became less parochial and opened up to learn of parallel European self-help/mutual aid as well as Asian and later post-Communist forays into developing SHGs. Section 4 details the societal contexts within various European countries that have affected SHGs’ relationships with professionals and how various political and resource contexts affect society-wide policy and practices impacting self-help/mutual aid. I am concluding this journey with some reflections on what is noteworthy about this research, summary statements of the impact of self-help/mutual aid, and suggestions for the focus of future research.

Three distinctive research traditions have been used as a fundamental organizing device in this review, as each tradition studied SHGs by writing within their own professional journals and were often unaware of others’ work. The North American addictions recovery tradition specialized in AA; the North American psychosocial tradition covered the remaining wide range of groups, but often excluded AA; and the European psychosocial tradition was interested in a wide range of groups, usually without AA, but was distinctive in examining SHGs’ impact on civil society and the larger society.

Several other noteworthy aspects of the research over the last fifty years will be mentioned: The research has been multidisciplinary, which has added more perspectives, methodological strategies, and approaches, greatly enhancing its diversity and richness. As a sociologist I have learned a lot, especially working with community psychologists who, in some cases, I thought were reinventing sociology, but whom I now see were inventing a more pragmatic, closer-to-the-ground sociology.

It is the voices of research professionals, however, that have primarily been heard in the body of mainstream literature throughout most of this era. If research professionals also had insider knowledge, like I did, they kept it hidden because of the damage that revealing it would do to their credibility and reputation as serious scholars. I regard the fact that professional journals increasingly publish work by people with dual credentials—such as professional degrees combined with experientially based identities as mental health consumer/survivors (e.g., Solomon, 2004), or researchers who are members of an SHG for men and their masculinities (Mankowski, 2014), or members of a 12-step/12-tradition group, as I myself have been—prima facie evidence that SHGs’ original monumental struggle against professional hegemony has been broken.

*Professional centrism*, coined by Rappaport (1994) and his colleagues, refers to professionals’ assumptions that although self-help/mutual aid is valuable, professional interventions are preferred and superior. Professional centrism has become less overt, but still exists in many subtle forms.

As scientific knowledge accumulates about various disorders, such as addictions, SHG research has changed somewhat in response. An example I like to use is that of AA, the target of so much criticism over the years. In the 1970s, AA was often depicted as an authoritarian organization (Gartner & Riessman, 1977, pp. 25–26; Katz & Bender, 1976b); it was also seen as accepting of a stigmatizing label (Goffman, 1963; Sagarin, 1969). The lifelong attendance was regarded as dependence, a view by some that AA replaced alcohol as a crutch. As medical science recognized that alcohol use disorders were chronic relapsing disorders that required lifelong recovery support, major researchers who had previously criticized AA as encouraging dependency for alcoholics changed their tune. Riessman in the 1990s devoted a chapter to “the special significance” of AA (F. Riessman & Carroll, 1995), and Katz (1993, p. 9) saw the 12-step/12-tradition anonymous model as one of two models of SHGs.

Some researcher networks studying self-help/mutual aid have been especially impressive in developing long-term collaborative relationships with SHGs that have changed and matured the researchers’ work. Here are the two previously mentioned examples: First, there is Rappaport and colleagues’ evolution from seeing GROW as simply a form of alternative human services to recognizing it as a caring community, one that converted members’ major identity from that of being patients of the mental health system into being members of a supportive community with part-time statuses as people who use mental health services. Second, Leonard Jason, Joseph Ferarri, and many others at De Paul University’s department of community psychology have been in a fruitful mutual relationship for twenty-seven years with Oxford House, an AA spinoff, that independently operates clean and sober, democratic, self-financed and self-run recovery homes around the United States and in some other countries (Jason, Ferrari, et al., 2006; Jason, Olson, & Foli, 2008). Generations of graduate students have learned research and launched careers partly on its basis, and Oxford House has gained the stature of official designation as an evidence-based intervention from the federal Center for Substance Abuse Treatment, among other benefits.

Regrettably, the networks of researchers in the United States never coalesced in any significant way to advocate for a more general federal policy of supporting self-help clearinghouses or other assistance to self-help/mutual aid in the health care system, as was done in Germany (see Section 4).

Methodology texts are concerned about the impact of the researcher on the content and subjects of the research (appropriately so), but is the reverse—the impact of the subject matter on the researcher—ever discussed? Other than the old and now problematic discussions of the anthropologist “going native,” I am unaware of any. But the above examples are instances where the researchers themselves have been influenced by the groups they are studying, and have needed to change their way of doing research to better elicit the nature of the group, or have themselves changed as a result. My hypothesis is that studying the fundamental features of self-help/mutual aid—with its emphasis on positive emotions (Vaillant, 2014), reciprocal helping and being helped, and the valuing of one’s story within egalitarian and respectful personal relationships—rubs off on the researcher, who is both humbled and inspired by the experience.

What has been the impact of fifty years of SHGs and SHOs? As I relayed in the story of institutionalization at the end of Section 2, I think SHGs have been successful in their *major challenge to medical dominance* in two key ways: greatly enhanced patient participation, and the voice of lived experience being recognized as legitimate, if still secondary to science and to the establishment. Patient participation in deciding one’s own treatment and health care is now taken for granted as an individual right, and not solely the right of the physician; being informed and choosing to engage in research or not are included under the rights of privacy to one’s health information; there is voluntary choice to engage in supplemental health services (especially for addictions, chronic diseases and disabilities, and serious mental illness through support groups, SHGs, or online groups); and there is patient representation in policy-making venues, to a greater or lesser extent.

The patient’s voice of lived experience has become valid and routinely heard. Physicians and other providers refer patients to SHGs, SHOs, and support groups, and worry less about the spread of misinformation when patients talk to each other. Self-help supporters are appropriately concerned about the fact that decision-making bodies often choose to feature celebrity or other nonrepresentative voices over the voice of a seasoned self-helper, whose collective experiential knowledge reflects more diversity and nuance.

With the success of the civil rights movement and other movements, African Americans and many voiceless, marginalized, or stigmatized groups have not only gained a voice in public, but also the right to name themselves. In 1970, when I started studying an SHG for people who stuttered, I referred to them as “stutterers” (see Borkman, 1976b), but by 1999, when my book was published, it would have been inexcusable to refer to them that way; instead I called them “people who stutter,” as stuttering represents only a small part of who they are.

Self-help/mutual aid has been implicit and hidden, if not invisible, in society. Granted, it is a minor intervention in that relatively few who are eligible to attend an SHG actually do so; and moreover, many of those who try it never return and we don’t know why. This is true of AA (Kelly & Moos, 2003) and other groups. However, in some health areas, SHGs have an outsized impact, namely serious mental illness (SMI) and alcohol use disorders (AUD). As discussed in the history of the mental health consumer/survivor movement in Section 2, by 2002 the number of SHGs, self-help advocacy organizations, and consumer-run services eclipsed the number of all psychiatric units in general and specialty hospitals and clinics; in short, mental health self-help/mutual aid, writ large, was an integral part (if a stepchild) of the mainstream mental health system.

In the area of alcohol problems, AA helps more people than mainstream professional services, even though the majority of those may be AA-inspired 12-step treatments (Institute of Medicine, 1990; McCrady & Miller, 1993). A study examining all of the SHGs for the twenty most life-threatening diseases in four cities had to separate AA groups from the total in any analysis, as they would otherwise swamp the remainder; they constituted 87 percent of the total (Davison, Pennebaker, & Dickerson, 2000). The researchers concluded: “The numbers, and hence the AA story, are a testament to the potential strength and efficacy of mutual support: The largest number and degree of health behavior changes in the country are the product of a network of largely anonymous, expert-free, cost-free groups whose sole purpose is mutual support” (p. 209).

Further, as shown in Subsection 3.3.2, AA and TSF (12-step facilitation administered by professionals) have been convincingly found by the Cochrane systematic review (Kelly, Humphreys, & Ferri, 2020) to be more effective in long-term abstinence, quality of life, and cost effectiveness than professional therapies.

Today, we are reinventing the wheel, as spinoffs—the equivalent of the neighborhood recovery centers and other social model recovery services developed in California in the 1940s to 1990s (Subsection 3.4)—are being rediscovered by the mainstream treatment establishment. Addiction medicine increasingly recognizes SUDs to be chronic and relapsing disorders that consequently require long-term, community-based recovery care after initial specialized professional treatment (White, 2009; White, Kurtz, & Sanders, 2006). Enlisting the recovering community to support them, especially as role models, and to develop new models of community recovery, is occurring (see, for example, Haberle et al., 2014). Unfortunately, the lessons learned from the California social model of recovery are rarely remembered, much less tapped for insight (an exception is Polcin et al., 2014).

One regrettable and glaring omission in this review is a discussion of research on internet groups, online chat rooms, bulletin boards, and social media. Unfortunately, I had not studied that literature in any depth, and then I ran out of time to cover them. Certainly, they have exploded in number, and one hears that some face-to-face groups are losing members to the online groups, but I have seen no data verifying that. There is evidence that face-to-face groups increasingly also use online or telephone groups or social media (Borkman & Munn-Giddings, 2020; Boyce et al., 2014). Such groups have become an important part of the social support landscape, but it appears to be difficult to distinguish member-run groups from professionally run groups, as the terms “support group” and “self-help group” seem to be used as synonyms. The volume of online groups is huge—a single day’s searching on the Bing internet search engine (May 25, 2020) returned 9,750,000 listings under support groups and 104,000,000 listings under self-help groups. With the COVID-19 pandemic, many face-to-face groups have had to resort to virtual meeting places, and we will not know the ramifications of that for years. Two interesting studies could be mentioned: one on how internet groups for functional syndromes (not accepted as diseases by medical establishment) can be both advocacy and support groups, and how cross-cultural differences are found in the groups partially due to health care services environment differences between Germany and the United States (Hearn, 2006); and another study on how men might be more participatory in internet groups by being more willing to self-disclose online than in face-to-face interactions (Salem, Bogar, & Reid, 1997).

As I finish this review in June 2020 in the midst of the coronavirus pandemic, we have been sheltering in place for over three months, and I will end with several observations. A colleague told me that several of her AA groups and Overeaters Anonymous groups she knew about started a virtual meeting about two weeks after the face-to-face meeting was suspended due to the pandemic (Shelly M., personal communication, April 13, 2020). I am struck again by the resilience of the 12-step/12-tradition anonymous model as a self-organizing learning environment (see Subsection 3.4), where some members relatively quickly replaced face-to-face meetings with online ones. I also learned of a new kind of SHG in China. Ximeng Chen studied SHGs in mainland China for parents who lost their only child in the context of the now-suspended one-child policy. She conducted personal interviews, often in their homes, with parent members of five of these groups in a large Chinese city. Three of the groups are primarily local face-to-face groups with supplemental online activities; the other two groups are primarily online and have members spread around the country. The groups had both personal social support and advocacy goals. The parents interpreted their loss as not only the death of their only child, but also the loss of their old-age security. They advocated for the Chinese government to compensate them financially for their loss within the context of the one-child policy (Chen, 2017, 2018, 2020). Finally, I remind the reader that this review is not about the actual prevalence and behavior of SHGs but what we know of them through research. New SHGs are springing up, and the coronavirus pandemic is sparking many new instances and forms of mutual aid.

What other lessons need to be learned to guide future research on self-help/mutual aid? We will conclude by proposing three issues to consider for future research: (1) reframing the relationship between SHGs and professionals, (2) reexamining the way we study social support and supportive communities, and (3) tackling the diffuseness of the concept of “peer support” by researching the helping process inherent in peer support.

In the course of reviewing, analyzing, and reflecting on materials for this review, and in conversations with and reviewing the work of Carol Munn-Giddings, my long-term collaborator and fellow self-help supporter, I now realize the need to reconceptualize the issue of professionals’ relationships with self-help/mutual aid. The North American psychosocial tradition (and I along with it) has—mostly implicitly—viewed the relationship rather simplistically in terms of power and control. Further, I have criticized much of the SHG research that overemphasizes any professional’s involvement with SHGs for being simplistic, since power and control did not seem to be considered and may not have been involved. I have not attended to, or I have ignored, comments (although I have heard them dozens of times) such as “My psychiatrist won’t give me therapy—unless I go to AA to stay sober.” That comment reveals that the psychiatrist has an implicit division of labor: they will only do therapy with a sober patient, but they can’t or won’t work to get the patient sober, yet they trust AA to do it for them. Along similar lines, it is interesting that a number of professionals in addictions recovery are focused on improving ways to introduce patients to AA so as to increase their likelihood of going and staying in AA, as it has been shown to be so effective. Whether it is TSF, MAAEZ (Kaskutas, Subbaraman, et al., 2009), or intensive referral to SHGs (Timko & DeBenedetti, 2007), professionals are working to improve patients’ chances of connecting meaningfully with AA, the non-professional free resource. This situation may be unprecedented since, according to social movement theory, once a lay initiative has become co-opted, as SHGs were with institutionalization—when some were renamed “support groups” and operated under professional control—then the remaining SHGs would be more likely to fall under professional control as well. The converse is happening. AA is behaving as the dominant player in the sense that professionals are designing new interventions to connect patients with AA (even though AA is silent on the matter, as it has no opinion on outside affairs).

To put a larger frame upon it, the open systems model of organizational analysis views organizations as existing in an environment, and this applies to professionals and SHGs as well: “That a system is open means not simply that it engages in interchanges with the environment, but that this interchange is an essential factor underlying the system’s viability” (Scott, 1981, p. 102).

SHG research has always considered some aspects of the environment to be important—for example, how important members are to recruit from the external environment. However, what else do SHGs need from the environment? As a case in point, researchers have rarely considered how important it is to an SHG to learn scientific knowledge of their focal issue of interest and concern from professionals, and in what ways it might be important and for what kinds of focal issues. Or are there other services from professionals that SHGs need? This kind of analysis should also consider whether professional involvement lessens or impacts the members’ sense of ownership, which is linked to their development of agency.

Using open systems theory, one could show both sides of the transactions. How do professional clinicians benefit from their clients’ use of SHGs? Do SHGs relieve professionals of patients with humdrum problems, allowing them to reserve their resources and energy for patients with more complex cases? Or in what ways, if any, do self-helpers complicate the work of professionals?

A second issue for future research is social support. As shown in Subsection 3.3.2, which focused on change dynamics and outcomes, social support is one field’s mechanism of change and another field’s outcomes. Social support is a major way of conceptualizing SHGs as SHGs—we call them “support groups,” which is also a definition they answer to. Within the supportive community interpretive framework, SHGs are inherently supportive, but they are rarely studied in any detail or with any depth as social support. Wuthnow (1994) calls SHGs the ideal form of community that is well matched to the conditions of modern life: they fit the mobile, transitory lifestyles of today, the shifting patterns of family, and the unwillingness to make major time and scheduling commitments for volunteering. Is social support all things to all people, but of significance to none?

Meanwhile, increasing scientific evidence is mounting of the criticality of social support for recovering from health crises, coping with chronic illness or disability, and even longevity. Social support, as expressed by having a supportive social network, a confidant, friends and family with whom to engage in social and recreational activities, or lack of loneliness, is vital—not tertiary—in its impact on these health outcomes. Lack of social support is on the cusp of being recognized as a risk factor in health on the same level as obesity, lack of exercise, smoking, or high blood pressure. As lack of social support is elevated to being a risk factor for health and longevity, more serious and in-depth research attention will be paid to it. Hopefully, this will draw more attention to research on the socially supportive aspects of SHGs. One promising area to explore is Mandiberg’s (2010) concept of “enclave community,” borrowed from research on immigrant ethnic communities. Enclave communities are part-time spaces, like Fountain House clubhouses (Karlsson, 2013; Staples & Stein, 2008) or mental health consumer/survivor-run wellness and recovery services (L. D. Brown, 2012; Clay, 2005), where people can spend the day in an accepting and non-stigmatizing community where they feel valued and useful; they can then face their stigmatizing environment with less vulnerability.

The final issue for future research revolves around peer support. Peer support, I would argue, has become another catchall phrase whose meaning has become more diffuse and vague. Widely used in the mental health arena, it is often used in such a way where “peer” is defined as people who have used or are using mental health services; people who have a diagnosis from the mental health establishment; or people who self-identify as having a mental health disorder (Clay, 2005; Solomon, 2004). This is far from the original meaning of “peer” in the early SHG research—*peer* meant that one identified with the person as having a similar disorder and being like the other in important aspects; it did not mean just having a similar social status of having used certain services. The mental health consumer/survivor area has lost touch with the original meaning of peer support. Now I see research attempting to empirically identify when a peer is a peer, as seen in the article by Clark et al. (2016) titled “What Makes a Peer a Peer?” In this study, researchers asked patients in a veterans’ mental health unit which of their statuses were important for them in that context to regard another as a peer: being a military veteran, African American, having PTSD (posttraumatic stress disorder), or having a substance use disorder? Patients’ answers ranked as important to their sense of having a peer in treatment the following statuses in the following order: having a substance use disorder, PTSD, and being a military veteran.

As mental health CROs became separated and distant from the SHGs that spawned them, and as they became registered nonprofit organizations whose charters did not allow them to do advocacy (which was their original goal) and they responded to the indirect control of governments through funding (as described in their history in Section 2), they lost track of the original meaning of peer support. In all likelihood it was the government funders who suggested definitions of peer such as “having had or still having mental health services.” Only an unusual place such as SHARE! (the Self-Help and Recovery Exchange, described in Case Illustration 9) remembers and operates on the basis of the original self-help/mutual aid terms. What can be done about this state of affairs?

Return to examining in-depth the helping process in various situations of peer support. Asking for help is demeaning (Benjamin, 2019; Schein, 2011), and giving help is enhancing. SHGs offset the downside of asking for help by assuring everyone they have valuable help to give and asking them for help. Help is mutual, not one-sided. The helpee is also a helper. So-called peer support in mental health CROs or mainstream agencies often attenuates or sacrifices the mutual aid aspect—peer support becomes one-way, given by the trained and credentialed person with a title like “peer supporter,” who is being paid for their work. How supportive is this for the helpee? Lehn Benjamin (2019) is developing an elaborate and sophisticated approach to analyzing helping situations and the details of the helping and being-helped relationship. Her approach would be very promising to uncovering in what ways “peer support” is supportive and how it is supportive in different situations.

In conclusion, I feel very privileged to have spent my career studying SHGs and also participating in some of them, and to have had this opportunity to review the field to which I’ve contributed. I had not read some of the articles reviewed here in forty years, so to some extent I revisited the field as an old newcomer. Thank you, again, to the many self-helpers I’ve interviewed, observed, had coffee with, and discussed your SHG with—I have been impressed by your courage to tackle tough personal problems and to extend your help to others so loving.