# VR 5.2–3

# Self-Help/Mutual Aid Groups and Peer Support: A Literature Review

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**VR 5.2–3 EDITOR’S INTRODUCTION**

**The Larger Academic Context of Self-Help and Mutual Aid Research in Voluntaristics**

Voluntaristics is a nearly fifty-year-old organized global interdisciplinary field, and also a fledgling academic discipline since about 1995 (Smith, 2016, 2019). One very major topic of empirical research and theory in this field has been voluntary (membership) associations, which are the historically the oldest and also the most frequent nonprofits found in every human society properly studied (Harris et al., 2016; Smith, 1997b). Such associations have had the greatest cumulative impact on sociocultural progress and ethical evolution in human societies since the Industrial and Organizational Revolutions, beginning circa 1800 ce (Smith, 2018, 2020). There are many ways to classify or categorize associations, as reviewed by Smith and colleagues (2016).

Smith’s *Tenfold* *Typology of Association Purposes* (Smith et al., 2016, p. 100) is as follows:

(quoted with the authors’ permission), with the overall average percentage of each type from a fifty-country survey noted in parentheses):

(1) Philanthropic/Charity-Social Service-Health/Medical-Education Associations (7% = Social Welfare; 4% = Health-Related)

(2) Political Influence-Advocacy-Rights Associations and Parties (4% = Political Parties)

(3) Social Movement Organizations/Associations and Activism (3% = Environment, Conservation; 2% = Peace Movement)

(4) Community Improvement-Protection-Economic Development-Poverty Alleviation Associations (4% = Local Groups; 2% = Third World Development and Human Rights [some may fit also in #3])

(5) Occupational-Economic Support Associations (farmers, factory workers [trade unions], white-collar workers [employee associations; unions], professionals, businesses-employers’ associations (3% = Labor unions; 3% = Professional associations)

(6) Religious-Ideological-Morality Associations (12%)

\*(7) Self-Help-Support-Improvement-Personal Growth Associations (5% = Youth Work)

(8) Sports-Recreational-Exercise Associations (8%)

(9) Arts-Music-Culture-Study Associations (7%)

(10) Sociability-Conversation-Conviviality Associations (3% = Women’s groups [some of these may fit also in #3])

(11) Other associations (e.g., hobby-games-garden-plants-animals leisure associations; environmental-ecology-flora/fauna preservation associations, automobile-trailer-caravan-travel leisure associations; investment-financial management clubs; residential associations [monasteries, communes]; family concerns-planning-birthing-child-rearing associations; infrastructure-support associations; deviant voluntary associations).

 Note that the type of associations whose research literature is reviewed in the current double issue of *Voluntaristics Review* 5.2–3 is listed as #7 above. Self-help/mutual aid groups were also included prominently in the United Nations’ *2011 state of the world’s volunteerism report* (Leigh et al., 2011). This type of association is quite recent historically, flourishing mainly from early in the 20th century, although some such groups have existed in European countries since many centuries ago (see pp. 393-395 in Munn-Giddings et al., 2016).

 Much research on nonprofits favors study of more formally organized and often bureaucratic nonprofit *agencies*, nearly always with some paid staff, as contrasted with voluntary associations, the majority of which are all-volunteer, lacking paid staff (Smith, 2017).

Self-help/mutual aid associations are usually all-volunteer and local in scope, thus being grassroots associations in common terminology (Smith, 2000). As such, these self-help/mutual aid associations participate in substantial research neglect by most academics active in voluntaristics (Smith, 1997a, 1997c). Nonetheless, research on associations, including grassroots associations, has been increasing substantially since about 2010 (e.g., Casey, 2016; Cnaan & Milofsky, 2008; Smith, 2015; Smith, Stebbins, & Grotz, 2016; Smith & Wu, 2020; Smith & Zhao, 2020; Soteri-Proctor et al., 2016). Research on self-help and mutual aid groups has also been increasing in the 21st century, as the present *Voluntaristics Review* double issue/book clearly demonstrates. We are fortunate to have these outstanding scholars in this subfield as the authors, particularly Professor Borkman. She has written for us a capstone article summarizing and elaborating her long and distinguished academic career studying, writing, and editing the main academic journal about her favorite topic.

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# Author Bios

## Professor Thomasina Borkman (75 words)

Thomasina Borkman taught sociology at George Mason University, Fairfax, Virginia, for thirty-two years. Her fifty-year-long research on self-help/mutual aid has contributed to its visibility. She expanded American research by collaborating with and mentoring European and Japanese scholars. Her concept of *experiential knowledge*—that lived experience is authoritative knowledge in self-help groups—won lifetime awards for research and theory contributions in professional associations of community psychologists and nonprofit organizations and voluntary action.

## Professor Carol Munn-Giddings (74 words)

Carol’s subject and methodological interests are complementary—they put direct experience of health and social care situations at the heart of research. She is exploring the distinctive contribution that a collective knowledge base, developed in self-help groups or organizations over time, can make to our understandings and conceptualizations of health and social care conditions. Carol specializes in undertaking and supporting participatory forms of research that engage citizens and practitioners as co-researchers in the research process.

## Dr. Melanie Boyce (75 words)

Melanie’s research is with groups of people who are often defined as marginalized due to their health and/or social situation—particularly women with multiple and complex needs. Her research emphasizes experiential ways of knowing, peer-led initiatives, and the ethics and politics of undertaking research with marginalized groups. Melanie is committed to feminist forms of inquiry and participatory methodologies that have practical and meaningful benefits for all those involved.

## Combined Bio of All Three Authors (294 words)

Thomasina Borkman taught medical sociology and organizational and small-group behavior at George Mason University, Virginia for thirty-two years. Her fifty-year-long research journey on self-help/mutual aid groups and organizations has contributed to their visibility, and she expanded American research by collaborating with and mentoring European and Japanese scholars. Her 1999 book, *Understanding self-help/mutual aid: Experiential learning in the commons*, is still widely referenced. She was on the planning committee of the Surgeon General’s Workshop on Self-Help and Public Health in 1987, and she has participated in various policy venues advocating for self-help/mutual aid. Her concept of *experiential knowledge*—that lived experience is authoritative knowledge—won lifetime awards for research and theory contributions in her professional associations: the Society for Community Action and Research (SCRA) and the Association for Research on Nonprofit Organizations and Voluntary Action (ARNOVA). Thomasina met Carol Munn-Giddings in Mexico City in 1996 when they presented on the same panel, the beginning of a fruitful collaboration of nearly twenty-five years.

Carol Munn-Giddings, Professor of Participatory Inquiry and Collaborative Practice, joined Anglia Ruskin University in Chelmsford, UK, in 1995 after many years as a social researcher and manager in health and social care settings. Carol has undertaken and supports participatory research in which she teaches citizens how to conduct research on their issues. She is especially interested in how citizens and citizen groups with direct experience of a situation can inform the improvement of health and social services. Carol has been Melanie Boyce’s mentor, and is now a collaborator; Melanie is a senior research fellow where Carol teaches, in the School of Education and Social Care. They have collaborated on research projects on mental health user-led organizations, service-user involvement, and self-help groups. Both are interested in experiential ways of knowing and peer-led initiatives.

# Abstracts and Synopses

## Synopsis (999 words)

English-language social and behavioral science research into US self-help/mutual aid groups and nonprofit organizations is reviewed. The review begins with the 1960s and 1970s, during the civil rights movement and other social movements, and proceeds into the new millennium, when institutionalized self-help/mutual aid was co-opted and renamed “support groups” by professionals. Independent self-help/mutual aid groups (SHGs) continue to exist, but are now seldom researched. SHGs are intentionally created, single-issue, voluntary, member-run mutual benefit groups that value the authority of lived experience and are cost-free, and where peers give and receive help from each other. They are variously described as mutual help groups, self-help groups, or self-help support groups.

Almost all self-help/mutual aid began similarly with democratic, egalitarian, peer-based values, using lived experience as authoritative knowledge expressed through narratives and stories in respectful personal relationships. Differences in societal attitudes toward SHGs, their own goals, organizational forms, and characteristics led them to develop in three sharply contrasting ways. They divided into three social movements: First, Alcoholics Anonymous, which is eighty-five years old and very large with many members and groups in the United States, Canada, and internationally, is oriented toward members’ personal recovery and engages in no advocacy. Second, ex-mental patients who were released from long-term hospitals without support or resources were angry at their inhumane treatment and advocated for changes in public mental health care. Third, the remaining SHGs and self-help organizations (SHOs) for physical illnesses, disabilities, and parents whose children had diseases such as cancer were termed the general self-help/mutual aid group movement; they were diverse in goals, activities, organizational forms, and their relationships with professionals and with scientific knowledge depending on the nature of and characteristics of their focal issue. The review foregrounds the fundamental values, principles, organizational forms, and processes of sustainable self-help/mutual aid that have endured, as well as the researchers, self-help clearinghouses, and government policy initiatives that supported their development and legitimized them.

The sheer existence of SHGs and SHOs was a challenge to medical sovereignty. They testified to people’s demand for greater participation in their health and social care and in the credibility of the voice of lived experience. Developed groups have *meaning perspectives* of belief and knowledge based on members’ experiential knowledge of the definitions and meanings of the groups’ focal issues. Told through the lens of medical sociology is the story of how self-help/mutual aid’s efforts (along with the health consumers movement and many changes in the medical profession and health care system) succeeded in dethroning medical sovereignty, increasing patient participation and involvement in their health and welfare, increasing visibility and respect for patients’ experiential knowledge, and destigmatizing health conditions and statuses by building positive identities.

Relatively few people eligible to participate in a SHG ever join. The limited evidence suggests that general self-help groups are comprised primarily of White, middle-class women, but the addictions groups are disproportionately male (as is the prevalence of substance use disorders in the population) and are more racially, ethnically, and socioeconomically diverse. The local, unregistered small-group format with voluntary participation creates methodological challenges for research. Since many experimental methods are inappropriate, participatory forms of research were developed to study them.

Borkman uses autoethnography (where the researcher becomes a participant in the study) to describe how her personal experience with feminist consciousness-raising, grieving, and 12-step/12-tradition anonymous groups provided her with extraordinary insights from being both an insider and a trained sociological outsider. The broadening of SHG research in the 1990s to encompass parallel research in Europe and Asia is described through Borkman’s personal odyssey of collaborative international research. Her international work illustrates significant differences in how self-help groups are shaped by social, economic, and cultural situations. British coauthors Munn-Giddings and Boyce contribute a section of the review with vignettes of six European countries, showing how societal context, including civil society, shapes the nature of self-help/mutual aid.

The multidisciplinary features of SHG research—from social workers, community psychologists, psychologists, sociologists, voluntary action scholars, public policy analysts, and nurses—is highlighted. Case illustrations are used throughout the text to provide in-depth analysis of specific issues, such as the contrast between Canadian health policy, which incorporated self-help/mutual aid and facilitated its development, and US health policy, which excluded it and complicated the process for self-help supporters to receive government support.

The characteristics and implications of different forms of organization, especially the small-group format that characterizes SHGs versus nonprofit organizations (registered tax-exempt 501(c)(3)s, the basis of most self-help organizations), are implicit themes throughout the review. The egalitarian, democratic, peer-based values and the central social technology of the sharing circle fundamental to self-help/mutual aid are more easily created and sustained in a small group. The nonprofit 50l(c)(3) is inherently hierarchical and vulnerable to professionalization and bureaucratization, which complicates the development of a sharing circle and the realization of the mutual aid ethos and its values. The downside of the small-group form is its structural vulnerability, which Alcoholics Anonymous has apparently solved with the 12-step model (program of personal recovery), whose organizational principles (12 traditions) include avoiding owning property, being financially self-supporting, and valuing democratic and rotating leadership. This model avoids some traps that can lead to a formalized organization that would threaten the sharing circle. The 12-step/12-tradition anonymous model has been copied by almost 100 other organizations, such as Gamblers Anonymous, Overeaters Anonymous, and Narcotics Anonymous.

Mental health consumer/survivor-run organizations and associated peer support operate in organizational environments that preclude mutual aid unless drastic steps are taken to equalize relationships between staff and participants and give participants opportunities to help others. A case illustration highlights SHARE!, a self-help/mutual aid-based organization in Los Angeles County that receives government funds for mental health consumer/survivor-run services; SHARE! has taken drastic steps to equalize relationships between staff and participants and provide opportunities for participants to help others. Because most mental health consumer/survivor-run organizations and their associated peer support preclude mutual aid, they are regarded as offshoots of the original self-help/mutual aid phenomenon and not direct descendants. Research attention has now switched to mental health peer support.

## Short abstract (99 words)

English-language social and behavioral science research into US self-help/mutual aid groups and nonprofit organizations (e.g., Alcoholics Anonymous, Parents Without Partners, or bereavement groups) is reviewed. The review begins in the 1960s and proceeds into the new millennium, when institutionalized self-help/mutual aid was co-opted and renamed “support groups” by professionals. SHGs are intentionally created, single-issue, voluntary member-run mutual benefit groups that value the authority of lived experience and are cost-free, and where peers give and receive help from each other. Research attention expanded to European and Asian research in the 1990s, but has now switched to mental health peer support.

## Long abstract (298 words)

English-language social and behavioral science research into US self-help/mutual aid groups and nonprofit organizations (e.g., Alcoholics Anonymous, Parents Without Partners, or bereavement groups) is reviewed. The review begins in the 1960s and proceeds into the new millennium, when institutionalized self-help/mutual aid was co-opted and renamed “support groups” by professionals. Independent self-help/mutual aid groups (SHGs) continue to exist, but are now seldom researched. SHGs are intentionally created, single-issue, voluntary, member-run mutual benefit groups that value the authority of lived experience and are cost-free, and where peers give and receive help from each other. Alcoholics Anonymous, specializing in small-group recovery without advocacy, developed so differently from mental health consumer/survivor groups’ intense advocacy against the mental health care system that their histories are described as separate health social movements. General SHGs for other physical illnesses, disabilities, and stigmatized conditions constitute a third social movement. The review foregrounds the fundamental values, principles, organizational forms, and processes of sustainable self-help/mutual aid, as well as the networks of researchers, self-help clearinghouses, and government policy initiatives that supported SHGs’ development and legitimized them.

Although few people eligible to participate in an SHG do so, the members become important reciprocal sources of sharing lived experience and giving and receiving mutual support. The broadening of SHG research in the 1990s to encompass parallel international research in Europe and Asia is described through Borkman’s personal odyssey of collaborative international research. The local, unregistered small-group format with voluntary participation creates methodological challenges for research. Since randomized controlled trials are inappropriate, participatory forms of research were developed to study them. British coauthors Munn-Giddings and Boyce contribute a section of the review with vignettes of six European countries, showing how societal context, including civil society, shapes the nature of self-help/mutual aid. Research attention has now switched to mental health peer support.

# Keywords

self-help, mutual aid, peer support, civil society, self-help groups, mutual help groups, mental health consumer-run organizations, grassroots organizations, voluntary action, participatory action research, Alcoholics Anonymous, nonprofit organizations

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I am very grateful to the countless self-helpers, self-help supporters, and colleagues who have taught me so much during my fifty years of research (and some personal participation) in self-help groups; I hope that my writing faithfully reflects and conveys your truths. What grand adventures my colleagues (particularly international) and I have had learning together the elusive complexities and diversity that is self-help/mutual aid. My sister, intimate friend, and editor Aina Stunz, I cherish your unwavering emotional support, editorial assistance, and intellectual insights—you always remember the goal when I am lost in the weeds. My husband, Placidus Ekwueme, uncannily knows the comforting action or words to offer and enthusiastically honors me for being myself. Audra Sim has been delightfully pleasant and the consummate professional in presubmission editing, copy editing, and polishing this manuscript and bibliography.I thank the reviewer, Linda Farris Kurtz, for her helpful and very constructive suggestions for improvement.

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# 1 Introduction

While mutual aid and voluntary action are ubiquitous in human history, their type, form, shape, and relationships to society vary extensively and are specific to the needs that are not being met by other institutions and interactions. During the 20th century, industrialized countries provided many citizens with a satisfactory economic lifestyle. Extended families, small intimate communities, and religious, racial, and ethnic bonds were loosening, and other forms of traditional social support were being replaced by nuclear families and a more secular, diverse, and impersonal social landscape. Psychology and psychiatry were developing talk therapies and biological medications to deal with emotional upsets, especially traumatic issues. It was into this situation that distinctive forms of self-help/mutual aid groups (SHGs) evolved; they were not new in kind, but had a particular constellation of features rendering them special as sources of knowledge to cope with or recover from illnesses or socially stigmatizing situations, and as sources of emotional and social support. Their important features were that they were single-issue, small-group forms of organization in which personal lived experience served as the primary basis of knowledge and authority; where egalitarian values and norms were practiced and reciprocal, noncommodified forms of giving and receiving help were the status quo; and where members had extensive control over the groups, which were typically at least semiautonomous. There are numerous examples of such groups in health and social contexts, such as groups for people who have various chronic diseases, mental distress, or addictions, or for parents whose children have cancer or rare genetic diseases, or have died. They operate as voluntary mutual benefit associations (Smith, 2000) in civil society, not in the marketplace. SHGs are therefore contrasted with philanthropic service organizations (such as Shriners International), political parties, and social and activity clubs (Borkman, 1999a; Katz & Bender, 1976b). This literature review will focus on selected aspects of the English-language research literature on self-help/mutual aid groups and organizations.

Having studied self-help/mutual aid groups for decades, I view the research broadly as falling within four research traditions (Borkman, 2008d, 2010b). Each tradition is comprised of a loose network of scholars and practitioners from different disciplines who focus on similar groups, favor specific methodologies, publish in the same specialized professional journals, and disproportionately cite one another; they tend to be unaware of other traditions, although a few people like Keith Humphreys (Humphreys, 2004; Kennedy & Humphreys, 1994), Linda Farris Kurtz (1997, 2015), and myself (Borkman, 1976b, 1997a; Kaskutas, Borkman, et al., 2014) contribute to at least two traditions. I label the four traditions as follows: (1) North American psychosocial, (2) North American addictions recovery, (3) European psychosocial, and (4) developing countries’ economic aid. This review focuses on the first three, mentioning the fourth only in passing because their focus is on financial aid and constitutes an entirely different form of mutual aid, thus entailing an almost entirely different literature base. The vast majority of research falls within two traditions: North American psychosocial and North American addictions recovery. The smaller European psychosocial tradition appears to have developed somewhat independently but increasingly refers to the North American psychosocial tradition, though they do publish in their own journals. The most thorough examination of research literature in this review is of the North American psychosocial tradition. The research of the European psychosocial tradition and the vast literature of the North American addictions recovery tradition are dealt with selectively.

The review covers only English-language literature on self-help/mutual aid groups and organizations and peer support. Self-help books, tapes, and other do-it-yourself phenomena are excluded. The literature deals mostly with social and behavioral science literature and does not systematically review papers in specialty journals in biology, medicine, or the like, although some are included when referenced by an author from one of the research traditions. Material self-help such as food cooperatives, neighborhood watches, and cooperative housing are mostly excluded because the literature excludes them. The “self” in self-help refers primarily to individuals, not to communities, cities, or societies (for example, “self-help” is used in political circles to refer to lesser entities, such as cities, funding and implementing projects with their own resources). Literature using the term “self-help” to refer to communities, cities, and the like is excluded here.

Overall, this will be a retrospective review of social science research literature on self-help/mutual aid and peer support primarily from the mid-20th century to about 2010, which is the heyday of research attention to self-help groups and self-help organizations. Current research, especially after 2010, emphasizes peer support and consumer/survivor-run or service user-run organizations, and is less germane to this review. A major concern is that the current generation of researchers knows about peer support and support groups, but does not know the peer support and support groups’ connection to self-help groups (Borkman & Munn-Giddings, 2020). The foundation of current trends in peer support (Davidson et al., 1999), peer workforce (Myrick & del Vecchio, 2016), and consumer/survivor-led or user-led initiatives (Brown & Wituk, 2010) rests on forms of self-help/mutual aid from the 20th century; yet, there has been a disconnect between the two literatures such that their very foundation is in danger of becoming lost or seriously compromised. To address this disconnect, the emphasis in this review will be to bring to the foreground the fundamental values, principles, and processes of sustainable self-help/mutual aid that have endured through half a century of social science research and criticism. The third tradition—the European psychosocial—is covered in part in Section 4 by Carol Munn-Giddings and Melanie Boyce, and will draw on older as well as up-to-date research. Their section deals with research from the different regions of Europe (Northern, Southern, Eastern, and Western) to show how societal governance, health and welfare systems, and civil society both shape the contours of peer support and self-help/mutual aid and respond to their form.

## 1.1 Concepts of Self-Help/Mutual Aid and Peer Support

Self-help/mutual aid and peer support have multiple definitions and meanings. Lay people often use various terms such as *self-help group* or *support group* interchangeably, but researchers carefully define concepts and terminology so that they are understood and in agreement.

“You alone can do it, but you cannot do it alone” is often used to describe the two aspects of self-help and mutual aid. *Self-help* refers to an individual (1) becoming an empowered activist in solving their life problems, (2) taking personal responsibility to resolve their problems, and (3) utilizing internal strengths to cope with difficulties (F. Riessman & Carroll, 1995). *Mutual aid* refers to peers in egalitarian relationships giving and receiving support and information, especially in the form of “lived experience,” to and from each other, where a defining feature is the mutuality and reciprocity where both are givers and receivers of help (Munn-Giddings & Borkman, 2018). A slightly different expression of this is F. Riessman’s (1965) well-known idea of the “helper” therapy principle, which states that peers who help others benefit the most. In other words, self-helpers receive help from each other and also give each other help.

The concept *self-help/mutual aid* is broad, inclusive, accurate, but awkward. Here it will be used as the general term to denote self-help groups, formalized nonprofit self-help organizations, or spinoffs that are voluntary and have features of self-help and mutual aid but differ in other aspects of their organization. Offshoots that may have a few characteristics of self-help or mutual aid but are either in the marketplace, controlled by governments or professionals, or not voluntary are too different to be considered self-help/mutual aid here. Professionally facilitated support groups are not included under the general umbrella of self-help/mutual aid.

The terminology researchers use for the same phenomena varies across time and somewhat by field, which can be very confusing. In the 1970s, “self-help groups” was the most frequently used term (Borman, 1975a; Gartner & Riessman, 1977; Katz & Bender, 1976b; Lieberman & Borman, 1976b), “mutual help” was a secondary choice (Caplan & Killilea, 1976; Silverman, 1978), while “peer self-help psychotherapy groups” (Hurvitz, 1976) was distinctive but was rarely picked up by other researchers. In the 1980s and 1990s, as community psychologists began to dominate the field of research, they preferred the term “mutual help” because it captured the mutually supportive atmosphere of the groups—the term “self-help group” suggesting an ethos of rugged individualism (Humphreys & Rappaport, 1994, p. 218). In 1976, Ed Madara, head of the New Jersey Self-Help Clearinghouse and American Self-Help Clearinghouse, preferred the term “MASH” (mutual aid self-help), although he used both that and “self-help group” in the seventh edition of the Clearinghouse’s *Self-help sourcebook* (White & Madara, 2002). But by the 24th edition in May 2009, the sourcebook was titled *The self-help support group directory* (Broderick & Rodenbaugh, 2009), and it seemed to use the terms “self-help group,” “support group,” and “self-help support group” interchangeably. Here we use the original term *self-help group* (SHG) for informal groups and *self-help organization* (SHO) to denote formalized nonprofit self-help organizations.

In the 1970s and 1980s, support groups were defined by researchers as professionally facilitated groups of peers with “lived experience” of a common issue who met to provide information and support to each other under a professional’s rules and procedures. Over time, as self-help/mutual aid became more taken for granted, terminology became less precise and more interchangeable. Careful researchers do not rely solely on the stated terms but look as well as the characteristics of the groups or organizations, and independently categorize a specific group or organization as fitting their definition of a self-help group, support group, peer support, or something else.

*Peer* is now used in several ways—first, to denote individuals who have the same focal issue and similar “lived experience,” which was the original way it was used in the self-help/mutual aid research literature (e.g., “peer psychotherapy group,” described by Hurvitz, 1976). However, around the turn of the 21st century, *peer* began being used in phrases such as “peer support” or “peer support provider” or meaning “consumer/survivor,” to denote individuals defined as similar in their having received or their now receiving mental health services (Clay, 2005). The advocacy organizations of the National Coalition of Mental Health Consumer/Survivor Organizations decided after much deliberation on the self-description of *consumer/survivor* (Fisher & Spiro, 2010). They define “peer” as those who, because of their experience with the mental health system, share a common bond (Fisher & Spiro, 2010, p. 222), “consumer” as those still using mental health services, and “survivors” as those who survived the mental health system (Fisher & Spiro, 2010, p. 213).

Peer support workers or specialists (or various other titles) often receive training and certification from the state; they often have paid jobs in consumer/survivor-run organizations (or “service user-run” organizations in Europe) or in mainstream, professionally based agencies (Myrick & del Vecchio, 2016). Since these peer support providers or peer support workers operate in organizational contexts in which they do not have egalitarian relationships with their fellow peers, but are rather in paid positions while their peer is a client or member, these relationships lack the mutual aid characteristic of self-help/mutual aid originally developed and still practiced in self-help groups. Therefore, they are not regarded as the same as original peer support in this review.

Cross-cultural terminological differences can be extensive, as we (Borkman from the United States and Munn-Giddings and Boyce from the United Kingdom) have found in working together. Alternative terminology can be offensive without intentionally meaning to be. For example, the mental health consumer/survivor-run organizations in the United States are referred to as mental health service-user organizations in the United Kingdom and other countries. “Mental patient” is still used, but “psychiatric patient” has negative connotations in the United States; the opposite appears to be the case in the United Kingdom and elsewhere. “Chronic disease” is a technical term used in public health, biology, and medical sociology in the United States, whereas it may be objectionable in other countries.

Frequently, I adopt the terminology used at the time period in question; for example, the mental health consumer/survivor movement began as “ex-mental patients” banding together in groups, and the literature of the time uses that terminology. While I do not intend to be offensive, my decision to use the terminology of the time period increases that risk. However, by neutralizing terms, which destigmatizes them, one cannot convey the meaning of the time. For example, when Alcoholics Anonymous (AA) was founded in 1935, people who drank excessively and caused problems in public were called “alcoholics” or “drunks.” To use the politically correct term now—people with substance use disorders—would lose most of the meaning of what AA members faced in public and from professionals. Would AA have become as successful if it had originally been named Substance Use Disorders Anonymous? Would we have a window into the change in societal attitudes if we obscured original terminology?

### 1.1.1 Definitions of Self-Help Groups (SHGs)

Even though SHGs were informal small groups, they were defined as intentionally organized to achieve a goal in order to distinguish them from the informal helping of friends, families, and neighbors. Katz and Bender (1976b) had the most specific and fully elaborated early definition, which was and still is often referenced:

Self-help groups are voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change. … Self-help groups emphasize face-to-face social interactions and the assumption of personal responsibility by members. They often provide material assistance, as well as emotional support; they are frequently “cause”-oriented, and promulgate an ideology or values through which members may attain an enhanced sense of personal identity. (p. 9)

Other characteristics of SHGs included the following: they often arise spontaneously, some are ad hoc and short lived (Katz & Bender, 1976b, pp. 9–10), they emphasize peer solidarity rather than hierarchical governance, and they tend to be self-supporting, relying on donations rather than grants or fees (Borman, 1975a, pp. vi–vii). Gartner and Riessman (1977) thought that the “the single most common important common denominator … is that the role of the person who has already lived through the experience is critical for helping others. Not only does that person know what it is like, but he or she has also learned how to play the required new role—the alcoholic who has stopped drinking … or the person whose spouse has died and now accepts the state of widowhood” (p. 67). This idea is similar to my concept of experiential knowledge (Borkman, 1976a).

The issue of the extent and kind of professional involvement in the group was and remains contentious among researchers. Further, the distinction between professional control and power on one hand versus professional involvement on the other was rarely made, which added to the confusion (see Borkman, 1999a). Unfortunately, the differences between professionals who were understanding of and supportive of self-help/mutual aid values, principles, and practices and those who were not, was not clearly distinguished until the idea of a “self-help supporter” was introduced in 2011 (Oka & Borkman, 2011). A “self-help supporter” is a professional, official, family member, 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” (Oka & Borkman, 2011, p. 16). Today it is more widely understood that there are a range of professional reactions to SHGs and SHOs and that self-help supporters can be involved in them without controlling or co-opting them (see Munn-Giddings et al., 2017; and Section 4 of this article).

More recent definitions of SHGs have proliferated—only several key ones will be mentioned here. To facilitate international comparative analysis, Gidron and Chesler devised the following definition: “the recruitment and mobilisation of peers in an informal and non-hierarchical setting and the sharing of common experiences” (1994, p. 3). A decade later, Humphreys (2004), who studied addictions SHGs in more than twenty countries, organized his definition in an appealing way by dividing it into seven universal and nine optional features. His universal features were the following: “members share a problem or status; self-directed leadership; valuation of experiential knowledge; norm of reciprocal helping; lack of fees; voluntary association; and inclusion of some personal-change goals.” The optional features were as follows: “developed philosophy and program of change; spiritual or religious emphasis; groups nested within a larger organizational structure; political advocacy; internet presence; membership by relations of the substance-abusing participant; defined role for professional; acceptance of external funds; and residential structure” (p. 14). Humphreys sidestepped the contentious argument about professional control versus involvement in the group by stating that the group had “self-directed leadership” (pp. 14–15), which would include any member as a possible leader. Defined roles for professionals was an optional feature.

The most recent set of researchers from various countries and continents (Munn-Giddings, Oka, et al., 2016) agreed on the lack of consensus on a single definition of self-help/mutual aid groups but concluded that there was agreement on three defining characteristics: “(1) SH/MAGs are run for and by people (nearly always volunteers) who share the same health, economic, or social problem or issue; (2) the primary source of participant’s knowledge about the issue is direct experience; and (3) these groups operate predominantly in the nonprofit sector” (p. 394).

The specific groups, collectives, organizations, and networks that early researchers included in their examples of SHGs varied even though they defined them as small groups. All excluded communes and frequently mentioned that they excluded food-buying cooperatives and other material mutual aid efforts (Katz & Bender, 1976b; Lieberman & Borman, 1976b). Gartner and Riessman (1977) restricted their studies to mutual aid for human services only. Katz and Bender (1976b) and the *Explorations in Self-Help and Mutual Aid* conference (Borman, 1975a) were probably the most expansive, as they included social change organizations such as the National Welfare Rights Organization, residential communities such as Synanon, and geographic communities such as Camphill Village in Scotland and a Mississippi community health project. Others excluded organizations that were only social change or geographic communities. Some included a wide range of collectives including networks (American Indian Ecumenical Conference; Borman, 1975a, p. 158), and combination residences, businesses, and self-help/mutual aid endeavors such as Delancey Street (Borman, 1975a). One interesting approach was the Toronto Community Self-Help program, which was composed of members from different anonymous and other self-help groups (remarks by MacDonald, as quoted in Borman, 1975a, p. 178). Silverman’s (1976) Widow-to-Widow program involved a one-to-one relationship between a widowed aide who had successfully dealt with widowhood relating to a new widow.

The autonomous self-help groups frequently mentioned in these early studies were Alcoholics Anonymous and Recovery, Inc.; other 12-step anonymous organizations such as Gamblers Anonymous, Al-Anon, and Narcotics Anonymous; life-transition-related groups such as La Leche League (for breastfeeding), Parents Without Partners, or Make Today Count; health groups related to new technologies such as United Ostomy Association or International Association of Laryngectomees (Silverman, 1978); and groups for physically disabled people (the blind, the deaf, and Little People of America). Gartner and Riessman (1976b) listed many health groups established by the 1970s women’s consciousness-raising groups (CR groups), and more generally the women’s health movement and Integrity were likely to be given chapters in books.

Integrity was an interesting anomaly in that it evolved in academia out of the rejection of conventional, professionally based therapy into a dialogic sharing of similar experiences among groups of six to eight lay persons (which could include professionals) based on the three principles of honesty, responsibility, and involvement (Mowrer & Vattano, 1976): “The main purpose of Integrity Groups is to help alienated (‘lost’) persons *recover their integrity* and thus *rescue themselves from an identity crisis*, actual or pending …” (p. 420). People who joined were usually well educated and middle class or above and who had a variety of issues; most other groups forming at that time were single-issue groups.

Later researchers in the 1980s and 1990s narrowed the kinds of organizations, collectives, and network they described as fitting their definitions of SHGs or SHOs. They often eliminated organizations that were involved only with social change and no personal change goals, and they also eliminated residential or geographic communities and network collectives (such as the American Indian Ecumenical Conference). Single-issue groups and organizations predominated both in their definitions and examples. Online groups and forums were added as they became available.

## 1.2 Differences between Self-Helper Peer Helping and Professional Helping Relationships

Self-helper peer helping relationships are often implicitly or explicitly compared with professional helping roles such as social worker, physician, or counselor. The nature of the peer self-helping relationship is fundamentally different from the professional or client one. “Peer support” and peer helping have become imbued with multiple meanings; the peer self-helper in an SHG is noticeably different from a “peer support” specialist or peer provider with training or credentials who has a paid job helping a client in a professionally based agency. This section applies only to the self-helper in an SHG or SHO, not to a peer provider in a mainstream agency. The professional and self-helper models of helping relationship are described within the organizational context in which they usually operate—the bureaucratic agency or the SHG (see Table 1). These fundamental differences are clearly delineated in several dimensions, including background, structure of the relationship, role boundaries, and view of the focal issue; the Table was compiled on the basis of my work (Borkman, 1990b, 1999a) as well as that of Hurvitz (1976), Katz and Bender (1990), Medvene and Teal (1997), White (2009), and Wilson (1995b).

Insert Table 1 about here

As Table 1 shows, the professional position is a specialized occupation based on certain education and credentials. The professionals’ personal stake in the situation is to maintain their position and career, although they are often also interested in helping to serve their clients. The professional relationship is hierarchically structured with the client in the subordinate position. In effect, the professional utilizes their professional expertise to help the client in exchange for fees or the equivalent. Relatively strict role boundaries are erected (although they can vary somewhat) according to professional ethics, the agencies’ standards, and the nature of the tasks. The professional is expected to maintain some distance from and “objectivity” toward the client, and does not become friends with them or part of their social network. The professional’s availability to the client is limited and usually scheduled by appointment or by day or week. Moreover, their expertise is relatively specialized and does not address all the client’s life issues—it most likely excludes existential or spiritual concerns, among other topics.

The self-helper peer-to-peer relationship, in contrast, is voluntary in many respects, not just in the basic choice of whether or not to participate in the SHG. The self-helper comes to the group with the troubling issue, often stigmatized, that is the focus of the group; when they identify with others with the same troubling issue, they becomes peers. The individual self-helper’s stake in the situation is highly subjective, personal, and they can be highly motivated to seek out the most effective way to alleviate their troubles. In that respect, they can have high standards and may be passionate and persevering in their problem solving. Their peers’ influence on them is largely based on the individual self-helper’s identification with them, and when the peers’ “lived experience” seems relevant as information or problem solving. The individual self-helper chooses how often, when, and how extensively to get involved and participate in the group, and with whom to associate outside the group. Help is usually available much of the time, as the group has a number of people who help each other and are willing to help inside and outside of meetings. All aspects of the focal issue of the group that affect one’s life can be addressed by the group, including existential questions (“why did this happen to me?”), spiritual concerns, as well as the selectively unhelpful reactions from one’s families or others to the troublesome issue.

The next subsection considers how I am both an outside researcher and an insider who has participated in SHGs personally.

## 1.3 Insider and Outsider Perspectives

The primary reviewer and author, I, Thomasina Borkman, have an intimate role with the subject matter. For half a century, as an outsider, I have conducted research and published in all three research traditions—extensively in the North American psychosocial tradition (i.e., Borkman, 1976b, 1999a), moderately in the North American addictions recovery tradition (i.e., Borkman, 2008a; Kaskutas, Borkman, et al., 2014), and sparsely in the European psychosocial tradition (i.e., Borkman, 1997a; Munn-Giddings & Borkman, 2018). As an insider, I have personally participated as a member in several self-help/mutual aid groups and a professionally led support group. I have personal experience with a variety of SHGs and support groups. Usually, a researcher’s personal participation in the subject matter under review is unknown, not discussed, avoided even, since it is still customary and normative in professional publications to write in an objective-seeming third person. However, I am breaking tradition and will be experimenting with a newer form of researcher reflexivity called autoethnography (Denzin, 2014; Ellis, Adams, & Bochner, 2011), which will be presented as case illustrations. These will cover a specific topic in some detail and will be introduced occasionally throughout the text to drill down in more depth on some research or autoethnographic event.

\* \* \*

Case Illustration 1

Autoethnography: A Researcher With an Inside and Outside Perspective

In graduate school in the late 1950s at Columbia University, which had a premier sociology department, I was taught that positivism and empiricism were sine qua non. Positivism emphasized causal relationships, and the gold standard of methodologies were the randomized controlled experiment or the double-blind randomized clinical trial. Sociology and other social sciences were new disciplines that were more scientific in name than performance and partly embraced positivism in order to garner respectability. Granted, we were exposed to Max Weber, a towering founder of sociology who spoke of *verstehen*, or empathetic understanding of social phenomena, but lip service was paid and little attention given to qualitative methodologies to accomplish *verstehen*. Increasingly positivism’s assumption that human observers were capable of objectivity without their culture, socioeconomic background, and basic roles such as race, gender, and age filtering their viewpoint was exposed as a myth by philosophers and the hard sciences such as physics; even as a young researcher, I questioned that myth.

My graduate training taught me the skills and ethics of being the outside observer—to be as objective as possible—which basically means being unrelated and unconnected to what you are studying. Ethics includes decisions about what you study: just as the physician is not supposed to treat his family members because he is too close to them and cannot be objective, the sociologist is expected to choose social phenomena to study that are somewhat distant from themself.

Autoethnography is a newer philosophy and methodology in which the trained researcher explicitly uses their lived experience as data and information that is reflected upon and written as social science (Denzin, 2014; Ellis et al., 2011). For example, Ellis recounts the last year in the life of her partner, whose chronic disease becomes terminal, and reflects on how those experiences relate to other social science knowledge on chronic disease and dying (Bochner & Ellis, 2016). Ronai (1992) writes about her feelings as a sociology graduate student earning her tuition by working as a pole dancer and her conflicts in assuming the identity of an erotic dancer.

I wish to consider how my dual perspective has affected my research and how I write about it going forward. I approach writing about this with some anxiety, as it upends the norms I have abided by for fifty years.

In 1970, as a first-year assistant professor with a new PhD, I started studying a group for people who stutter. I identified them within a year or two as a self-help group, which was an emerging concept with a relatively sparse literature. According to the theory of the day, they shouldn’t even exist because stutterers have difficulty talking to one another. Yet, they did.

In 1972, in keeping with the feminist social movement arising in the country, I joined a female consciousness-raising group (CR group) organized by the National Organization for Women. As I recount in an essay (Borkman, 2013a) in *Footnotes*, the newsletter of the American Sociological Association, I was almost ejected from the group, as I did not know how to discuss my personal experiences with discrimination in the workplace or other experiences as a female in society. Instead, I brought in national statistics on female wage discrimination and similar data. My objective training had temporarily incapacitated my understanding of how to reflect on my life and tell my personal story based on lived experience—which was exactly what communication consisted of in the group of people who stuttered, the CR group, and other equivalent groups I was researching. From my (inside) participation in the CR group and concurrent (outside) observation of the self-help group of people who stuttered, I developed the seminal concept for which I am professionally well known: *experiential knowledge*, or the knowledge and wisdom based on personal lived experience as the primary basis of authority and communication in self-help groups (see Borkman, 1976a). In retrospect, I do not think I could have developed the concept of experiential knowledge, particularly so early in my self-help group research journey, if I had not had both the inside and outside experiences simultaneously, and if I had not gone through the humiliation of nearly being rejected by the women’s group.

In 1972–1973, I obtained a small grant from the university to research three SHGs that varied in their reliance on professional knowledge as a secondary source of knowledge. The 12-step/12-tradition anonymous group Alcoholics Anonymous (AA) was selected as using professional knowledge minimally; the group of people who stutter were midway, as they relied on speech therapists to improve their fluency but were critical of how limited the effectiveness of the therapies were; and an ostomies group, focusing on a new medical procedure that provided a substitute for nonworking bladders, were highly dependent on medical knowledge. Comparing the three groups allowed me to understand that reliance on professional knowledge was the obverse of depending on lived experience as authoritative. This work contributed to and refined my formulation of experiential knowledge and its application to self-help groups.

In 1977, as a result of a personal crisis, I joined a 12-step/12-tradition anonymous group—a type of group exemplified by groups such as Gamblers Anonymous, Overeaters Anonymous, or AA. I am honoring the 12-step/12-tradition anonymous groups’ rule against identifying yourself in public as a member of the group by not revealing which group I joined, but forty-two years later I continue to attend its meetings. I joined a second 12-step/12-tradition anonymous group in 1980 and have also attended it for years. I attended a professional and self-helper co-led grief group in 2005–2006 and a professionally led breast cancer support group in 2012–2013.

Among other insights gained from studying the three contrasting groups (in tandem with participation in the CR group) were questions about how they were organized and other issues of organization, which was a specialty area of sociology in which I had been trained. For example, the CR group after a year or more “finished” our work of consciousness-raising and came to a crossroads: Do we disband or continue as a social club having parties, lunches, and other social events? We chose to disband but knew of other CR groups that continued as social clubs. This behavior was contrary to bureaucracies, which maneuver to maintain themselves at all costs.

While I was trained to do formal organizational analysis of bureaucracies and formally constituted, officially registered, tax-exempt nonprofit organizations, the research on small-group behavior was a separate specialty. SHGs involved both small-group and formal organizational behavior. Over a period of years I participated on the small-group level (the 12-step/12-tradition anonymous groups) and was attending to organizational issues as well in my research. At some point, my university department needed someone to teach a course on small groups—I volunteered even though I needed to do extra work to master the research on small-group behavior. In hindsight, I think my personal participation, along with my hours of observation of small-group behavior in the SHGs I had researched, had given me valuable experiential and professional knowledge of small-group dynamics. Incidentally, I usually received the highest student evaluations from the Small-Group Behavior course than from any other course I taught. Thus, my research and personal experiences—my outsider and insider perspectives—furthered and enriched my professional academic work.

\* \* \*

## 1.4 Outline of the Review

This introduction, Section 1, has briefly considered the definitions and characteristics of contemporary self-help/mutual aid and addressed the scope of the review. Section 2 will cover the North American traditions in three ways: First, the evolution of the research literature, depicting the history of three separate but overlapping social movements (Alcoholics Anonymous as a partial social movement, the general self-help group social movement, and the mental health consumer/survivor social movement) in relation to broad societal changes such as the civil rights and women’s movements. This survey will extend from the 1970s to the turn of the 21st century, by which time self-help/mutual aid had become institutionalized. Second, the infrastructure in support of self-help/mutual aid that developed is briefly described in terms of the social scientists and maverick professionals who researched and supported self-help groups, self-help clearinghouses, and resource centers, as well as health policy and governmental support. The third part of Section 2 is a narrative that summarizes the story of how the initially radical self-help/mutual aid of the 1950s to the 1970s, along with the aid of other societal forces, became part of the established landscape as it successfully overcame the major challenges they had experienced in mainstream systems with institutionalization.

Section 3 considers the content and findings of research—especially from the 1980s and 1990s—on topics such as (a) the development of international research; (b) methodological challenges necessitated by the voluntary, informal, and local character of self-help/mutual aid and how they are met through innovative collaborative and participatory action research approaches; (c) findings of research on who tries, joins, and stays in groups; on intragroup dynamics; and on the benefits, outcomes, and liabilities of groups for individuals and society; and (d) illustrations of important “spinoffs” and “offshoots” that developed with elements of self-help/mutual aid while differing in significant ways. Spinoffs are defined following Borman’s (1979) definition as “connected ideologically to the original groups but not organizationally affiliated” (p. 39). Borman gave examples of spinoffs from AA such as Narcotics Anonymous, Gamblers Anonymous, and Overeaters Anonymous. *Offshoots* are a category I created and named that are hybrid initiatives that combine elements of self-help/mutual aid and professional models, but where participants do not run the organization.

Section 4, written by guest authors Carol Munn-Giddings and Melanie Boyce from the United Kingdom, will focus on how the nature of the government, health and welfare system, culture, and civil society in various European countries shape the nature and contours of self-help/mutual aid and are in turn informed by it. Two issues are posed and addressed through vignettes of various European countries. First, the relationship of SHGs to professionals within the context of a country’s government health and welfare system and civil society is viewed through vignettes of the United Kingdom, Germany, and Croatia and Slovakia. Second, recent developments in the implementation of self-help/mutual aid initiatives are viewed through vignettes of Norway and Greece, revealing extensive changes in the understanding of and possible misuse of the concept of mutual aid.

Section 5 concludes with an assessment of the present state of self-help/mutual aid research and some suggestions for future research.

# 2 North American Self-Help/Mutual Aid Social Movements

## 2.1 History of Contemporary Self-Help/Mutual Aid Social Movements

Mutual aid has been a predominant part of human activity since the dawn of organized groups, clans, and tribes. The revolutionary Russian Kropotkin ([1902] 1972) counters the theory of human being as predator with examples of cooperation and mutual assistance that increased chances of survival among early groups and throughout history. Alfred Katz and Eugene Bender (1976a), social workers who were among the earliest to study self-help groups, point to the continuing cooperative and voluntary mutual aid efforts over the centuries. During the period of early industrialization, so-called friendly societies, outgrowths of the guild system, helped members who were sick, bereaved, poor, old, or otherwise infirm; examples of occupational groups mentioned from each century include the Incorporation of Carters (1555), the United General Sea Box (1634), and the Goldsmith’s Friendly Society (1712). “Before 1800, 191 such societies were founded,” Katz and Bender wrote (1976a, p. 268). Economic cooperatives were another form found in Europe and transplanted to the United States in rural and farming communities, or often in the form of trade unions in the cities (Katz & Bender, 1976a, p. 273).

The massive waves of immigration to America, especially after 1880, brought immigrants whose many adjustment problems were mostly resolved when they turned to each other for mutual assistance (Katz & Bender, 1976a, p. 275). See Wang (2016) for an entire issue of *Voluntaristics* *Review* that is devoted to ethnic and immigrants’ associations, including self-help/mutual aid groups.

Katz and Bender’s (1976a) history did not mention mutual aid groups for alcoholism or other addictions. In contrast, William L. White (1998, 2004) and others (e.g., Humphreys, 2004) focused on them. White’s detailed history of AA and the professionally and scientifically based alcoholism movement will be relied upon throughout this section. Note that he decided to use the language “that was popular within that era to convey not only the ideas but the words that dominated both of those periods” (White, 1998, p. xvi). The earliest mutual aid in alcoholism were the Native American recovery “circles” documented between 1737 and 1840, in which messianic leaders achieved sobriety through conversion-like experiences; they then started new religious and cultural revitalization movements (White, 2004, p. 532). Temperance societies were helping American alcoholics in the 1830s, and as the temperance movement grew, mutual aid groups were organized by and for “hard cases”—as those with severe alcohol problems described themselves. The Washingtonian temperance movement of the 1840s is probably the best known, as its failures were influential in the way the cofounders of Alcoholics Anonymous designed their groups (E. Kurtz, 1979). For example, alcoholics who got sober in the Washingtonian movement told their stories as public confessions and engaged in explicit political advocacy (O’Halloran, 2008; White, 1998); within a year of about 600,000 alcoholics becoming sober, the Washingtonian movement apparently collapsed as the members resumed drinking (White, 1998). AA cofounders, in order to circumvent the mistakes made by the Washingtonian movement, focused on a “singleness of purpose” to help the still suffering alcoholic maintain sobriety and avoid political advocacy or controversy (AA Tradition 10). Other mutual aid societies for alcohol recovery collapsed with the beginning of alcohol prohibition and the decline of 19th-century treatment organizations (White, 2004, p. 533). In Europe, various mutual aid alcohol societies emerged between the 1850s and 1870s, such as Blue Cross in 1877 in Switzerland (Humphreys, 2004, p. 54; White, 2004, p. 533).

Each era created forms of mutual aid and cooperative endeavors designed to meet the era’s immediate needs. This section provides first a history of contemporary self-help/mutual aid groups as social movements, then of the infrastructure of maverick professional researchers and practitioners who supported the development of SHGs as well as the accompanying public policy and governmental support. The final part tells the story of how the radical SHGs of the 1950s to the 1970s, along with other societal forces, led to major changes in the mainstream health and welfare systems and the institutionalization of self-help/mutual aid.

The origin of contemporary single-issue SHGs is often marked by the founding of Alcoholics Anonymous in 1935 and Recovery, Inc. in 1937 (now Recovery International) to help ex-mental patients and “nervous” people. A historical overview and summary from the standpoint of our current knowledge about SHGs and SHOs in the research literature will set the stage for then examining what happened chronologically from the 1930s to about 2020, as self-help/mutual aid evolved from unknown small groups to institutionalized peer-based therapies and distinctive forms of social support (Archibald, 2007). The emphasis will be on the US groups and secondarily on the Canadian ones, since I, as the observer, live in the United States, and the US research literature is the largest source of research about the US groups; this literature also constitutes part of the North American psychosocial research tradition and the North American addictions recovery tradition.

Early research studied groups in great detail to ascertain the key elements of the peer relationship, self-help, and mutual aid, primarily through extensive participant observation, in-depth interviews with leaders and members, and analysis of groups’ materials. Often self-help/mutual aid was initiated as a small group at the grassroots level by the people in need; as it evolved, the usefulness of more formal organization developed. The early research identified and explained major elements and principles of mutual aid of many small groups (as will be discussed throughout, the mutual aid dynamics of the small group inherently change as the organization formalizes). Current research on peer-led groups often seems unaware of the fundamentals discovered in this early research. Major aspects of the structure and process are important to elucidate because they differ dramatically from professional therapies and services; they were essentially “gift relationships” in civil society rather than professional–client fee-for-service relationships in the marketplace.

### 2.1.1 Key Elements of Self-Help/Mutual Aid Common to Early Groups

The early research on SHGs recognized that the basis of membership was (1) having a common troublesome issue that was important to the members and (2) using their similar personal lived experience as the basis of finding solutions to these issues and learning from each other how to deal with the issue (Borkman, 1976a; Gartner & Riessman, 1984; Katz & Bender, 1976b; Silverman & Murrow, 1976). Whether one is a peer with another in the SHG context depends both on (1) the individual’s recognition of a commonality and identification with others that makes a difference to the individual (Shapiro, 1990; Silverman & Murrow, 1976), and (2) the group as a collective forming around perceived commonalities that are important to the members. Often, the commonalities are found in the group’s name (e.g., Alcoholics Anonymous, Parents Without Partners, Parents of Murdered Children, Bipolar UK).

Mutual helping is regarded as a fundamental process in SHGs, as critical a characteristic as experiential knowledge (Borkman, 1999a; L. D. Brown & Lucksted, 2010; Shapiro, 1990). Shapiro (1990) defines mutual helping as “helping of any kind that takes place between persons who are regarded as both potential help-givers and potential help-seekers” (p. 169). He describes the SHG group movement as “a formalized extension of mutual helping, although each group may define its interest or concern in a particular way, and may formalize its rules and procedures in its own way” (p. 170). Frank Riessman coined the “helper” therapy principle in 1965: “Paradoxically, it appears to be much easier for someone to give help than to receive it, and giving help aids the helper more than the recipient. … The essence of the self-help group is giving help and benefiting from giving. … In self-help, people with problems are potential help-givers, more interdependent than dependent” (F. Riessman, 1997, p. 10). The self-help and mutual aid movement importantly revolutionized the concept of helping, according to Riessman. In many surveys on the benefits of participating in an SHG, helping others is often very high on the list of benefits (see, for example, Corvin et al., 2013; L. F. Kurtz, 1997).

In the safe small-group setting of an SHG, mutual helping is fundamental to and defines the essential process. Participants contribute to each other by their presence, their listening, and by sharing their personal lived experience of some aspect of the common issue during the central activity of the group—what I describe as the *sharing circle* (Borkman, 1999a). The “circle,” a distinctive social technology, is a dedicated meeting usually closed to nonmembers in which official literature approved by the group or a topic is discussed; participants take turns sharing about their lived experience following the explicit and implicit procedures and rules. It is usually more dialogic in nature than competitive, similar to ordinary conversation (Borkman & Munn-Giddings, 2017; Mäkelä et al., 1996). A participant’s presence also connotes a willingness to define themself as having the focal problem of concern to the group (research indicates that many people avoid groups precisely for this reason; L. F. Kurtz, 2015). Even suffering newcomers are regarded as helpful in reminding old-timers of what they were like before they began recovering.

The process of sharing experience about different facets of the common issue reveals similarities and differences to the participants. As the process continues, they evolve beliefs about the characteristics of the issue; the cause, if relevant; the natural history of the issue; reactions of family, friends, strangers and society; and workable and unworkable ways of dealing with it. These ideas and beliefs evolve into a codified “ideology” (Antze, 1976), “worldview” (Kennedy & Humphreys, 1994), or *meaning perspective* (Borkman, 1999a) that in established groups is well known to long-term members and is also found in the group’s official materials.

The leadership in SHGs has been described as democratic, egalitarian, or a “shared authority system” (Katz & Bender, 1976b, p. 113). Leadership positions are often rotated among members (in 12-step groups, chairing the meeting is so simple that almost anyone can fill in if the leader for the day is absent). “Officers of self-help groups do not possess authority simply because of the prestige they have in the outside world. … The authority and sanction of leadership is achieved or earned rather than ascribed” (Katz & Bender, 1976b, p. 114). An exception may be groups created by a founder who maintains leadership and control (Block & Rosenburg, 2002; Medvene & Teal, 1997). Other sources of status (such as socioeconomic status, neighborhood lived in) are usually minimized within the group by implicit rules discouraging discussion of them (Jensen, 2000; L. F. Kurtz, 1997; Mäkelä et al., 1996; O’Halloran, 2008). Race and ethnicity deserve a separate discussion and are considered in Section 3.

Since the basis of knowledge is the personal lived experience with the focal problem expressed as stories, members who have successfully resolved the common problem become positive role models and possess experiential authority within the group because of their deepened experiential knowledge and its application (Noorani, Karlsson, & Borkman, 2019). The power differential between the old-timer and the newcomer is slight, however, since they are peers, and is closer to that of friendship than of a professional–patient relationship (White, 2009, p. 16).

To recapitulate, the major characteristics of the peer relationship in the SHG context are (1) perceived commonalities of illness, social situation, or stigmatized condition to and identification with one another that are important to the individual; (2) relying on personal lived experience (experiential knowledge) communicated as narratives or stories as the basis for problem solving and dealing with the focal issue; (3) evolving a belief system or *meaning perspective* about the issue and how to resolve it; (4) mutual helping and the “helper” therapy principle in the sharing circle as key and essential technologies; and (5) veterans or old-timers who successfully recover or effectively cope with the shared problem developing experiential authority within the group while (6) all peer relationships are of roughly similar rank in nonhierarchical relationships with a small power differential between the veteran and the newcomer.

What follows here is a list of the commonly held principles and values that underlie the peer relationship and self-help/mutual aid, based on a statement and list from F. Riessman’s (1997) well-known discussion of the topic and augmented by material from the Self-Help Network of Kansas’s *Why self-help groups work* handout (*c*. 1990) and my own additions. Principles of egalitarianism, anti-bureaucracy, and respect among peers (Borkman, 1999a; Campbell, 2005; Chamberlin, 1990; Katz, 1993; E. Kurtz & Ketcham, 1992; F. Riessman, 1997) were held by groups of all varieties. By the end of the 1980s, commonly held key principles and values were as follows:

1. “Peer” is defined as recognizing each other’s commonalities; a special empathy and instant identity.
2. The group or organization is owned and run by its members; participation by outsiders is restricted.
3. If and how professionals are involved is determined by its members.
4. Personal lived experience expressed as stories is the knowledge base and the authority.
5. Help is not a commodity but a “gift.”
6. The “helper” therapy principle: Helping others means helping oneself.
7. Mutual-help relationships: Peers are both help givers and help seekers.
8. *Meaning perspective*: Ideas about how the focal issue is defined and how to cope with or resolve it are created or adopted by group.
9. Egalitarian and nonhierarchical relationships are emphasized.
10. A caring social network or alternative family-of-choice is often created.
11. Relationships are personal by first name.
12. Participation is voluntary; individuals choose how often, how intense, and how long.
13. *Self-determination*: A member’s right to choose and self-direct their changes is emphasized.
14. Normalizing and destigmatizing attitudes and practices are encouraged.

### 2.1.2 Three Overlapping but Separate Health Social Movements

We turn to the state of the field of self-help/mutual aid in the 21st century as examined from the vantage point of today’s analyses and understandings. First, self-help/mutual aid had become institutionalized by the year 2000. Second, major differences in goals, activities, and organizational strategies evolved over time to result in what I view as three distinctive social movements. The three social movements overlapped and were fluid and loosely organized, yet each was distinctive in a variety of ways, especially in their outcomes.

By the year 2000, self-help/mutual aid was widely known, taken for granted, and practiced in various ways—that is, institutionalized (Archibald, 2007). We (Borkman & Munn-Giddings, 2020) identified four strands of practice: (1) the original autonomous member-run groups continue while new ones for emerging issues spring up in civil society; (2) key ideas of self-help/mutual aid are borrowed and refashioned in spinoffs (spinoffs being SHGs with similar *meaning perspectives* but that are not organizationally related to original SHG) or offshoots (again, hybrid initiatives with both mutual aid and professional elements); (3) professionals have co-opted the central idea of peers sharing lived experience in safe settings and now run professionally led groups renamed as “support groups” in hospitals and clinics; and (4) entrepreneurs and others co-opt ideas from self-help/mutual aid and monetize them to make money in the marketplace.

Whether self-help/mutual aid groups in the United States constitute a social movement has been contested by sociologists and other researchers who study them, because many groups are neither explicitly political nor unified by coherent ideologies or organizational structures (Bloomfield, 1994; Katz, 1993). Alcoholics Anonymous is sometimes referred to as a partial social movement (Bloomfield, 1994) and is often separated from other self-help groups because of its gigantic size, organizational structure, philosophy, and impact, which are so different from other SHGs. I do not find it fruitful to debate the many opinions and arguments about the issue; instead, following the sociologist Archibald (2007), self-help/mutual aid groups will be regarded as a health social movement here. Archibald relied on Phil Brown and colleagues’ definition of health social movement, which I quote here:

Health social movements (HSMs) are an important political force concerning health access and quality of care, as well as for broader social change. We define HSMs as collective challenges to medical policy, public health policy and politics, belief systems, research and practice which include an array of formal and informal organisations, supporters, networks of cooperation and media. HSMs make many challenges to political power, professional authority and personal and collective identity. These movements address (a) access to, or provision of, health-care services; (b) disease, illness experience, disability and contested illness; and (c) health inequality and inequity based on race, ethnicity, gender, class and/or sexuality. (P. Brown & Zavestoski, 2005a, p. 1)

Health social movements are instances of new social movements “that involve collective action that is oriented toward social and cultural change like other social movements but emphasizes the importance of how the (collective) identity of the participants unfolds in the activities of the movement, rather than simply focusing on the rational goal-seeking behavior of participants” (Archibald, 2007, p. 32). Self-help/mutual aid groups are health social movements because they all address at least the psychological stress of stigmatized statuses even if they are not obviously health-related, such as being gay, divorce, or adoption (Archibald, 2007, p. 33). Their definitive characteristic as a health social movement is that they provide psychosocial support groups, where persons in similar situations share their lived and embodied experience in a closed and safe setting (Archibald, 2007, p. 33).

After recently studying the ex-mental patient liberation movement in the context of general self-help groups (Borkman, 2019), I now recognize that it is useful to divide self-help/mutual aid groups and organizations into three social movements, because they evolved under differing societal conditions with different goals, organizational structures, activities, and resulting outcomes. The three movements are (1) Alcoholics Anonymous and the 12-step/12 tradition addictions recovery groups; (2) the general self-help/mutual aid group movement, which includes groups for illnesses, diseases, disabilities, life transitions, and stigmatized statuses (Back & Taylor, 1976; F. Riessman & Carroll, 1995; Toch, 1965); and (3) the ex-mental patients liberation movement (Bluebird, 2009; Chamberlin, 1978; Emerick, 1996; Zinman, 2009), which grew into its new name of “mental health consumer/survivor” social movement by the year 2000.[[1]](#footnote-1)

The sociologist Robert Emerick (1990), who conducted a 1988 national survey of mental health mutual aid groups, argued that all self-help/mutual aid groups fit the sociological criteria of conventional social movements since they were politicized—they advocated for legal and other changes in professional treatment of them and for their civil rights. However, all of Emerick’s examples and references were to mental health SHGs, not to general SHGs for widowhood, nursing mothers, people with lupus, diabetes, or arthritis, or 12-step addiction groups. He was accurate in his arguments that mental health SHGs as a whole fit the traditional definition of a social movement, but he failed to realize that his examples and references were all mental health groups. Many of the ex-mental patient groups were significantly different from addictions groups or general SHGs in the degree of politicization, confrontation with authorities, and their emphasis on legal and civil rights and changing professional treatment, which are major reasons why I regard the three types of groups as constituting distinct but overlapping social movements (Borkman, 2019).

A brief summary of each of the three movements follows; the specific societal context in which each initially developed and their goals, forms of organization, major changes in direction as they evolved, and current status and impact are described. Among the reasons the three social movements evolved separately were the differences in societal context, including attitudes and institutional practices toward people in their specific situation. The organization ecology theoretical framework applies here (see Hannan & Freeman, 1989), which views individual organizations as

an entity that occupies a niche both in the community and in the health care and human services systems. The niche of the group is defined by the type of focal problem that members share, and by the geographic and interorganizational environment in which the group is located. Both the internal characteristics of mutual-help groups and the external environments in which they function are assumed to influence the organizational life-cycle and visibility of groups. (Maton et al., 1989, p. 644)

### 2.1.3 Movement 1—The Alcoholics Anonymous Partial Social Movement

Alcoholics Anonymous was founded within a troubled social and economic context in 1935. The world was in an economic depression. In the United States, alcoholism was a continuing problem even though alcohol had been legally unavailable during Prohibition. The mutual aid societies of the 19th century had disappeared, many earlier treatment facilities had closed, and Prohibition had just been repealed (White, 1998). Alcoholism was regarded as a moral failing. Drunkenness was primarily dealt with by the criminal justice system: drunks were put in jail for disturbing the peace. Medical and health care professionals regarded alcoholics as public nuisances, and the few extant medical facilities were for end-stage “wet brains” in mental hospitals. Some psychologists regarded alcoholism as a form of mental illness (White, 1998).

At AA’s beginning, cofounder Bill Wilson had become inspired by his then-abstinent friend Eddy who had been treated by the psychiatrist Carl Jung in Austria. In Bill’s last hospitalization in New York City, he had had a vivid spiritual experience and been “struck” sober. Bill began talking to other alcoholics in order to stay sober. On a business trip to Akron, Ohio, he was introduced to then-drunk Dr. Bob, a practicing physician, and told Dr. Bob his story of getting sober (E. Kurtz, 1979). “Bill W.” (as he is more widely known) and Dr. Bob, the cofounders of AA, regarded its founding date as June 10, 1935—when Dr. Bob became abstinent. A thorough and meticulously researched history of AA up to the 1970s was conducted by Ernest Kurtz as his PhD dissertation in American civilization at Harvard and was published as *Not God: A history of Alcoholics Anonymous* (1979). Three officially AA-approved books about the history of AA and recommended by White (1998) are *Alcoholics Anonymous Comes of Age* (AA, 1957), *“Pass it on”* (AA, 1984), and *Dr. Bob and the good oldtimers* (AA, 1980). A recent history of the founding of AA based on extensive archival records disputes some accepted understandings about the cofounders and how the major text, *Alcoholics Anonymous* (AA, 1939), was written (Schaberg, 2019).

Both cofounders belonged to the Oxford Movement, a religious movement recreating local groups of Christians with many proselytizing elements. Within the first three years of AA, the cofounders hosted local groups in Akron, Ohio, and New York City and struggled to find ways to help alcoholics sustain sobriety, adapting ideas from the Oxford Movement and other places. Their major text with the 12 steps (originally six steps, borrowed from the Oxford Movement) was written by Bill W., with extensive input from members in both groups (E. Kurtz, 1979) and was published in 1939 as *Alcoholics Anonymous: The story of how one hundred men recovered from alcoholism*. The 12 steps are the program of personal change that, when followed, help the alcoholic to maintain sobriety (L. F. Kurtz, 1997). With the book, a *Saturday Evening Post* magazine article by Jack Alexander in 1941, and other media assistance, word rapidly spread of the new mutual aid group. AA groups multiplied around the country and in Canada. From the beginning, Canadian groups were included with those in the United States for purposes of national-level conferences and decision making.

In AA’s early years, the co-founders considered developing more professionalized money-making enterprises, but they backed down at the insistence of other members and outside influences (Schaberg, 2019). The wealthy philanthropist Rockefeller turned down his request for a large sum of money, saying it would ruin the growing society (E. Kurtz, 1979). As groups around the country multiplied and experienced growing pains, they would contact the New York City office. Bill W. answered their questions by referring to the experiences of other groups—the authority of experience—rather than as a founder attempting to control the situation (AA, 1957). The cofounders complemented each other: Bill W. initiated big visions that were often unrealistic while Dr. Bob was more cautious but steady and reliable, and members of groups expressed their opinions, were heard, and mediated between extremes. By the late 1940s the groups had accumulated enough experiences with sustainable group functioning that the 12 traditions (suggestions for group structure and norms) were developed, discussed, approved by the groups, and codified in the second major “text”—the “12 and 12” (*Twelve Steps and Twelve Traditions*; AA, 1952).

The AA group had evolved an unusual form of autonomous small-group organization: the local groups controlled and made decisions through regional representatives of the groups to a yearly national conference. The nationally incorporated organization became a servant organization that did publishing, protected copyrights, and engaged in public relations for the membership and its groups. AA’s distinctive 12-step/12-tradition form of organization has survived the death of its founders, been copied by other groups, spun off related innovations, inspired many forms of co-optation, and withstood bureaucratization, professionalization, and the iron law of oligarchy. The local groups have a single goal, are financially self-supporting, are autonomous except as their behavior affects other parts of AA, and are governed democratically by members, all while maintaining voluntary and self-defined membership (you are a member if you say you are). Members can create new local groups: “All you need are two members with a resentment and a coffee pot to start a new meeting” (proverbial AA statement).

AA’s 12-step program has become recognized by psychiatrists, psychotherapists, and other professionals as a sophisticated, complex, and paradoxical program of personal transformation and second-order change (S. D. Brown, 1993; E. Kurtz, 1982). Early theorists (such as Dr. Harry Tiebout, a psychiatrist who worked with AA in its early stages, and Gregory Bateson, anthropologist, among others; see Bateson, 1971; Tiebout, 1944) conceptualized AA’s program, which psychotherapist Stephanie Brown (1993) subsequently interpreted as follows: Recovery in AA involves abstinence from alcohol plus transformative second-order changes in beliefs and behaviors in order to create a self that can maintain abstinence. Practicing the 12 steps within the context of the meetings and social support of the fellowship provides a path to these transformative changes (other analysts use the religious framework of “conversion”; see Petrunik, 1972). Briefly, the drinking alcoholic has a mistaken belief in their own power to control their drinking within a competitive framework of dominance and submission that they believe they can win (Bateson, 1971; S. D. Brown, 1993; Tiebout, 1944). When the alcoholic “surrenders” (i.e., gives up the idea of self-control over alcohol), they are free to replace it with a complementary framework of a “power greater than oneself”—the spiritual aspect of the program—and of being an equal to other people. “Acknowledgement of lack of control functions as an equalizer—a universal reminder of human frailty” (S. D. Brown, 1993, p. 144). “This thinking—that dependency is a natural and normal aspect of human development—matches current psychoanalytic views” (S. D. Brown, 1993, p. 145). Brown concludes: “The work of recovery involves the development of autonomy, grounded in acceptance of one’s basic human dependence and the development of mature interdependent relationships with others. Paradoxically, by relinquishing a belief in self-power, people in recovery experience themselves as autonomous and empowered from within” (S. D. Brown, 1993, p. 151).

Other 12-step/12-tradition addiction groups that are spinoffs and unrelated organizationally to AA, such as Narcotics Anonymous (founded 1957), Cocaine Anonymous (founded 1982), and Gamblers Anonymous (founded 1957), copied the 12-step/12-tradition model of AA. Mutual aid alternatives to AA also evolved: Jean Kirkpatrick was unhappy with the male orientation of AA in rural Pennsylvania and started Women for Sobriety (WFS) in 1976. Secular Organizations for Sobriety (SOS) was initiated in 1986 in reaction against the religiosity and spirituality of AA in the 1970s. Others followed, but they were never very numerous or geographically widespread; see Humphreys (2004) for a thorough discussion of AA and other addiction groups in the United States and in over twenty other countries.

The 12-step/12-tradition AA recovery movement is distinctive (1) in being the largest SHG, both in terms of number of groups and number of members; (2) in creating an organizational structure of autonomous, self-funded, member-run local groups with one nationally incorporated nonprofit organization based on the 12 traditions or organizational principles, which has lasted for over eighty-four years; which (3) has been a model form of self-help organization that has been copied by eighty to one hundred groups (White & Madara, 2002); and that (4) has inspired many peer-run spinoffs such as the Oxford Houses and California’s social model addiction recovery of the 1950s to 1990s; and (5) inspired many offshoots *s*uch as the Minnesota Model, a hybrid treatment organization of professional and 12-step ideas; (6) contributes to the public health and to reduced health care costs as a nearly cost-free space/place for hundreds of thousands of alcoholics to gain and maintain recovery; and (7) impacts society in major ways despite its stance on “having no opinion on outside affairs,” and thus has a hidden and submerged character in civil society (see Bloomfield, 1994); and (8) precipitated a national, if not global, recovery culture and movement.

AA has also consistently been the target of repeated and zealous attacks in the media and criticism from many quarters for its “religious” or “spiritual” emphases, attacks by feminists for its patriarchal nature, as well as challenges claiming it is ineffective; W. L. White (1998) lists ten major intellectual and other criticisms of AA with extensive academic and popular references (e.g., Bufe, 1991; Fingarette, 1988; Herman, 1988). Even sympathizers criticize its male orientation, and that it is too White dominant and unwelcoming to Black, gay, and other minority groups. Many of these criticisms will be addressed in Section 3 of this article.

Despite its critics, which AA ignores (as it has no public voice), AA’s quiet influence through its many members, family members, sympathizers, and imitators has evolved into a recovery culture (Room, 1992) on a national if not international level. In the United States, the recovery culture is omnipresent: television sitcoms, Hollywood movies, songs, and national advertisements reference AA and recovery ideas and images. Screenwriters, actors, and creative advertising executives belong to AA in private, and many places have 12-step cafés and bookstores that carry recovery materials while cruise ships’ bulletin boards have notices for Friends of Bill W. to meet at place X at time Y. Importantly, the recovery culture embraces the fundamental idea that addiction is a chronic relapsing condition (not a short-term bad habit) from which recovery is possible; recovery constitutes abstinence or remission plus the development of a productive and constructive life as a citizen that is self-directed and managed with the aid of recovery supports, family and friends, and professional services as needed (White, 2009). Alongside the voluntary, non-monetarily oriented recovering members of AA, other 12-step groups and addiction SHGs are parallel, entrepreneurial, for-profit-oriented recovery initiatives. These include recovery treatment centers combining professional and borrowed 12-step ideas that offer expensive services and run businesses producing 12-step paraphernalia such as buttons, bumper stickers, books, magazines, and the like (F. Riessman & Carroll, 1995, p. 71).

While AA grew, developed, and evolved a recovery culture, a related but mostly separate movement developed among professionals, scientists, and the government—referred to by William White (1998) as “The Modern Alcoholism Movement,” which covers the period from 1935 (the founding of AA) to 1955, and is important for its cultural redefinition of alcoholism and beginning of scientific research on alcoholism as a medical problem.[[2]](#footnote-2) White’s *Slaying the dragon: The history of addiction treatment and recovery in America* (1998) is used here to summarize the major changes in three periods pertinent to the story. Alcoholism was redefined as a disease (which is secular), and not a moral failing (which is religious); the source of the problem was changed from the nature of drink to the nature of the drinker. A public crusader, Marty Mann (one of the first women in AA), established what became known as the National Council on Alcoholism and Drug Dependence, and was a very effective reformer for over thirty-five years, changing the public and professionals’ views on alcoholism and its treatment. The essence was that “the alcoholic was a sick person, worthy of help, who could be helped, and that alcohol was a public health problem toward which public resources should be allocated” (White, 1998, p. 263). White regards the concept of alcoholism as a disease to be “an organizing metaphor that was useful both individually and culturally” (p. 198). The Yale Center of Alcohol Studies initiated a summer training session, encouraged research on alcohol, and initiated the first scientifically based peer-reviewed journal on alcohol research during that era.

The second period, which White called “Mid-Century Alcohol Treatment,” from 1956 to 1966, saw the birth and spread of the offshoot Minnesota Model as well as many spinoffs of AA, such as the documented California social model of alcohol recovery (Borkman, Kaskutas, & Barrows, 1996; J. Room, Kaskutas, & Piroth, 1998)—a state-funded system of AA-imitation recovery programs staffed by recovering alcoholics (Borkman, 1986). Professional medical and legal associations advocated that the problems of alcohol and drug addictions be moved from the criminal justice system to public health and medicine. The third period from 1965 to the end of the century saw the development of new occupations and professions of addiction counselor and addiction specialties in medicine, among others; the separation of alcohol and drug problems as primary diseases rather than secondary diseases of mental illness; and the development of a community-based system of addiction treatment in the United States through congressional legislation for federal initiatives and funding. In the early 1970s, Senator Howard Hughes (known privately as an AA member) initiated legislation to establish separate agencies for alcohol problems (National Institute on Alcohol Abuse and Alcoholism [NIAAA]) and drug problems (National Institute of Drug Abuse [NIDA]) that legitimated them as primary diseases, not symptoms of mental illness. These federal agencies funded a system of community-based alcohol and drug treatment agencies, established new occupations and professions to staff treatment centers, and funded scientific research on alcohol and drug issues.

Recovered alcoholics played an extremely important role in shaping the modern alcoholism movement, but their contributions were usually hidden behind personal discretion or AA anonymity (White, 1998, p. 194). Further, government agencies and professionals in the addictions field seemed to be ambivalent, behaving contradictorily by sometimes acting in public as if AA did not exist and failing to acknowledge its importance or contributions while privately conceding its existence.[[3]](#footnote-3) They were intent on professionalizing the field of addiction treatment and encouraging a scientific approach, to which they saw AA as antithetical.

The increasing professionalization and medicalization of alcohol and drugs led to the demise in the 1990s of the peer-based California social model alcohol recovery programs, which depended on state-level government funding (Borkman, Kaskutas, & Owens, 2007); the exceptions were self-funded sober living homes and Oxford Houses.

Alcohol and drug treatment were separate fields in the 1960s and 1970s and isolated from each other; the integration of alcohol and drugs into addiction treatment took the field thirty years of clinical experience and scientific research (White, 1998, p. 268). Research and clinical experience changed the concept of “alcoholism” to multiple forms of alcohol problems and to addiction as a chronic disease, like diabetes or hypertension, that was characterized by episodes of remission or relapse (White, 1998, p. 290). These multiple subpopulations had varying treatment and recovery needs, some of which did not involve lifelong abstinence or affiliation with a 12-step program (White, 1998, p. 290).

White recounts how the rapid growth of addiction treatment facilities in the 1980s funded by health insurance programs and governments led to entrepreneurs profiteering and competing and many ethical breaches. Recovering addicts were exploited. The health insurance companies and other agencies responded by drastically reducing their support and funding (White, 1998, pp. 283–285). Managed care systems were initiated to control costs and quality. White describes the addiction treatment field by the end of 1990s as “a panicked field in search of its soul and its future” (White, 1998, p. 286).

As research and clinical experience had advanced, those with mental health problems *and* alcohol or drug problems were studied as distinct populations. As they became more clearly delineated with separate treatment protocols, recovering individuals responded by initiating new mutual aid groups for both problems, such as Dual Disorders Anonymous, founded in 1982, and Double Trouble in Recovery, founded in 1993 (Kelly & White, 2012; Laudet et al., 2004). Self-help addiction groups were a regular part of addiction treatment, often as aftercare or follow-up after professionalized and specialized treatment.

Around the year 2000, the public health system began to combine addictions and mental health into “behavioral health.” Long-term recovery-oriented community-based mutual aid initiatives are being developed, such as consumer-run mental health organizations funded by state and local governments; and, in the addictions sphere, AA, Narcotics Anonymous, Cocaine Anonymous, and, increasingly, non-12-step mutual aid alternatives such as Women for Sobriety, LifeRing Secular Recovery, SMART Recovery, and others are being nurtured (White, 2009). AA so dominated the field, and the other SHGs were so small and geographically limited, that policy makers called for developing and supporting the SHG alternatives to AA to provide patients and addicts with more choices (Kelly & White, 2012).

Medical addiction science increasingly recognized that alcoholism and other drug addictions were chronic relapsing diseases (White, 2009), rather than acute illnesses requiring short-term treatments from which individuals graduated into short-term aftercare. Chronic relapsing diseases require long-term care such as recovery-oriented systems of care building on networks of SHGs and other community supports. Mainstream treatment systems therefore began endorsing broad constructs of recovery. The federal Center for Substance Abuse Treatment (2005) held consensus conferences that resulted in the following definition: “Recovery from alcohol and drug problems is a process of change through which an individual achieves abstinence and improved health, wellness, and quality of life” (p. 5).

### 2.1.4 Movement 2—The General Self-Help Group Movement: 1950s to 2000

In the mid-20th century, medical sovereignty reigned supreme; patients were taught to follow their physician’s orders. The era of infectious and communicable diseases’ domination of health care was loosening its hold as longevity increased and the larger number of older people in the population developed chronic diseases such as hypertension, diabetes, heart disease, or arthritis. As chronic diseases increased in prevalence, care shifted more and more to the patient. Lowell Levin (1990, p. 126) estimated that 85–90 percent of all health care, not just chronic disease care, is borne by the patient and their family, not the physician, health care team, hospital, or clinic. The patient has to take their prescriptions, plan special diets, and engage in exercise or other regimens at home and on their own terms, engaging with the health care system only periodically. (Unfortunately, the importance of social support in health, preventing illness, and increasing longevity has yet to be researched to any extent.) But the health care system was slow to recognize these changes and determine what modifications were needed to accommodate them.

A cultural revolution, which began in the late 1950s and accelerated in the 1960s and 1970s, accompanied the civil rights movement of Black protests against injustices and discrimination—involving women’s liberation, the anti-Vietnam War movement, gay rights, patients’ rights, and disability rights, among other causes. Hundreds if not thousands of local self-help groups for new illnesses, stigmatized social statuses, and other medical conditions sprang up partly in response to the activism oriented toward curbing social injustices. The movements challenged institutionalized authorities (including government), argued for more citizen participation and control, and valued knowledge from lived experience while challenging the hegemony of professionals (Wuthnow, 1994). The self-help/mutual aid social movements shared many of the same ethics, concerns, and principles with the civil rights, women’s, disabilities, and other social movements, although their goals, organizational ideals, and activities differed.

The general self-help group movement comprises the widest spectrum of conditions, encompassing almost all chronic diseases, illnesses, and disabilities; transitional states such as divorce, adoption, and widowhood; as well as stigmatized statuses such as being family survivors of suicide. Correspondingly, it encompasses a wide array of types of group and organizational structures; varies in the number and types of goals and the mixing of advocacy and member-coping goals; and its relationships with professionals are on a continuum from practically no contact to almost total dependence, often correlated to the nature of the illness, disease, disability, or condition (Shepherd et al., 1999). The nature of member benefits and outcomes also vary widely.

So many focal illnesses and conditions are included here that the diversity of goals, organizational forms, activities and trajectories over time is extensive. Major differences that affect the type and functioning of the group are the expected duration of the focal problem and the accompanying degree of change in lifestyle, circumstances, and identity that members believe they need to undertake to achieve satisfaction. I (Borkman, 1999a) categorized groups by whether the members of a group believed the focal problem was of short duration (such as two years or less) or long-term, and whether members expected to make minor changes in coping or major changes in identity and lifestyle. This resulted in two major categories: short-term groups dealing with coping or minor personal changes and long-term groups dealing with major personal identity changes. Note that the evaluation is made from the group’s and its members’ point of view, not that of an outside observer. Life stresses and transitions such as widowhood, premature infants, or divorce are short-term groups expecting help with coping and minor personal changes. Long-term major change groups tend to be the addictions groups or those suffering major disabilities such as blindness, deafness, paraplegia, or chronic debilitating conditions such as Parkinson’s disease or multiple sclerosis; here, participants expect help with major behavioral, lifestyle, and identity changes.

Different SHGs for the same problem can define the solution differently. For example, AA has defined alcoholism since its founding as a lifelong addiction that requires a major change in lifestyle, identify, and personality in order to maintain sobriety and serene recovery (AA, 1939); in contrast, SMART Recovery, a hybrid SHG, defines alcohol problems as learned behavior or a bad habit that can be turned around in a short time and requires only minor behavioral changes (Horvath, 1999; Humphreys, 2004).

A second way of categorizing SHGs was Leonard Levy’s (1976) three-fold classification of the nature of the focal issue and its solution as life stress, behavior control, or medical conditions. Life stress refers to usually short-term and often transitional statuses such as getting divorced or becoming a widow; persons from families with other focal issues are included here, such as Al-Anon for families of alcoholics. Behavior control pertains to the addictions or other conditions for which the mutual aid solution is to exert more or less control over one’s behavior. Medical conditions could be either acute (e.g., stroke) or chronic (e.g., multiple sclerosis). Maton et al. (1989) used Levy’s classification to study SHGs in the New Jersey Self-Help Clearinghouse’s extensive database in 1984 and in 1986, finding 3,125 groups over the two-year period. The five largest life-stress groups in their database were Al-Anon, Alateen, Parents Without Partners, widow groups, and Toughlove. The five largest in the behavior control category were AA, Overeaters Anonymous, Narcotics Anonymous, Emotions Anonymous, and Gamblers Anonymous. The five largest medical condition groups were for multiple sclerosis, stroke, physical handicap, visual impairment, and diabetes.

The life stress groups are often of short duration and regarded as involving minor changes in coping and lifestyle adjustments. Studies of NAIM, a two-decade-old grief group for widows in Chicago, found that members in groups often grieved actively for about two years, after which they often evolved into sociability groups whose members wanted leisure time social activities (Steinberg & Miles, 1979). The exceptions among life stress groups are family groups whose family members have addictions or mental health problems—often those groups define their issue as long-term and requiring major changes to accommodate the family member with lifelong issues of addiction or mental health problems (e.g., Al-Anon for spouses and family members of alcoholics, or Alateen for adolescent family members of alcoholics; see Humphreys, 2004).

The forms of organization among the general SHG social movement also vary. On one end of the spectrum, they can be local grassroots groups affiliated with a national organization such as the Anonymous groups (for the most part); unaffiliated local grassroots groups of volunteers, perhaps with informal officers; or democratic groups with rotating chairs or leaders. At the other end of the spectrum, they can be formalized as incorporated, paid-staff, nonprofit organizations such as 501(c)(3) groups that are tax-exempt and listed in public databases and the *Encyclopedia of associations*.

Several examples can help illustrate this range of organizational forms: The CR groups connected to the women’s liberation movement of the 1960s and 1970s were democratically run, informally organized small groups, intended for women to share their personal lived experiences of discrimination and prejudice as females in the workplace, health care system, family, schools, and other institutions of society. CR experience was seen as a stepping stone to becoming involved in women’s activist and advocacy groups (Bond & Reibstein, 1979). Parents Anonymous, atypical in that a professional supports the peer leader (Willen, 1984), was founded by Jolly K. and a professional social worker in order to reduce abuse and prevent abusive parents from hurting their children. Jolly K., herself an abusive mother, chose a form of organization of the peer with the problem and a professional who serves as sponsor of the group, believing that the professional presence provided protection to members, contributed with ideas, therapies and solutions, and further legitimated the group. Nonetheless, the professional serves at the pleasure of the peer leaders, and the organization describes itself as using a “parent-as-leader model” (Lieber, 1984; Willen, 1984, p. 109). A self-help organization of people who stutter (Borkman, 1976b) was an incorporated not-for-profit 501(c)(3) that had officers and other measures of formalization, although it operated mostly as a small group with a sharing circle. In this group, having officers as formal leaders with responsibility was important because the nature of stuttering led many to avoid taking responsibility or making commitments in situations that required talking.

The degree of formalization of the group or organization is related to the kinds of goals, activities, and benefits they choose. Case Illustration 2 describes how different kinds of Candlelighters groups of parents of children with cancer have varying goals and activities (Chesler & Chesney, 1995).

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Case Illustration 2

Diversity in Groups for Parents of Children With Cancer in the 1980s

Little research on multiple SHGs of a single type has been done to show patterns of similarity and diversity across SHGs for the same condition. The sociologist Mark A. Chesler and his students and colleagues are exceptions (Chesler, 1991a; Chesler & Chesney, 1995; Chesler & Yoak, 1984). From a national sample of over 300 support groups and SHGs for parents of children with cancer associated with Candlelighters, the national organization for parents of children with cancer, Chesler and Chesney (1995) chose a geographically representative sample of fifty organizations to study in depth; they conducted interviews with leaders and members as well as an analysis of the groups’ records and materials. Even though *n* = 50 is a relatively small sample, lessons can be learned from it. Importantly, they included all groups, which included professionally led support groups (*n* = 13, or 29 percent) as well as parent-led SHGs (*n* = 26, or 46 percent) and some hybrid groups co-led by parents and professionals (*n* = 11, or 25 percent). Groups were categorized into *formal* (incorporated with tax-exempt status, bylaws, officers, and committee structure), *semiformal* (some but not all of the formal elements), and *informal* gatherings (none of the above formal elements).

Findings of the fifty groups as a whole indicated that half had a small active core (two to seven people) and that 62 percent of groups had existed for three years or less. The degree of formalization was fairly diverse: 32 percent were highly formalized, 24 percent semiformal, and 44 percent were informal gatherings. The majority (62 percent) had small budgets of $1,000 or less. A large majority (70 percent) retained parents as members after the child dies; that issue was contentious in some places because the needs and perspectives of those with living or dead children were so different. A majority (52 percent) met in treatment centers, 36 percent met in community centers, and 12 percent met in homes. The vast majority (82 percent) had at least a few links with other local organizations. The majority (78 percent) had vertical links to the national Candlelighters organization; 56 percent used the Candlelighters name (Chesler & Chesney, 1995, pp. 138–141).

The professionally led support groups were all organized as informal gatherings. They had smaller memberships and budgets; were of shorter duration; and had a smaller number and variety of activities in comparison with the other two groups. Their primary activity was giving emotional support to families at meetings, with secondary activities of providing information or education and holding social events such as parties or picnics for parents and their children. The researchers concluded that the professionally led support groups had no reason to develop a formal structure, since the professional staff running the group did all the organizational work for the parents, and, in fact, the staff “owned” the group. Chesler and Chesney (1995) noted that “these groups also were likely to be too dependent upon the staff to openly challenge individual medical staff members or the organization of care” (p. 140).

The SHGs and the hybrid groups tended to vary structurally from the support groups: They were more likely to be highly formal or semiformal in organization, to be larger, and to have existed for more years (three to five years, or over five years), with an active core of attendees and mailing list. They had a larger number and variety of activities, including emotional support at meetings, one-to-one network support on the telephone or in person-support between parents outside of meetings, business meetings, fundraising events, social events, and advocacy efforts to change the medical system to meet the needs of families (Chesler & Chesney, 1995, pp. 138–139). Chesler regarded the SHGs and hybrids that advocated for system change as social movement organizations, but saw those whose only internal goal was helping members cope with the stresses of a child with cancer as quasi-social movement organizations (Chesler, 1991a, p. 300). However, Chesler concluded that “in all such groups there is an implicit challenge to the professional monopoly and ideology of service. And all such groups help empower their members” (1991a, p. 300).

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The issue of informal groups evolving into formalized organizations that became professionalized and bureaucratized appeared early in the academic literature. Alfred Katz’s first research (1961) was a study of four SHGs founded by and for parents of handicapped children; he found that within five years, three of the four had evolved into formalized organizations largely controlled by professionals rather than parents. However, after observing many other SHGs, Katz and Bender (1976b) concluded that the tendency of SHGs to become professionalized was not inevitable, and this was because of the values of member-led groups and democratic participation (pp. 122–123). The 12-step/12-tradition form of self-funded independent local groups with a national organization is a structure that affords a form of protection against professionalization and bureaucratization (Borkman, 2008b).

An organizational issue not raised in the literature is if and how the same groups change their type of leadership over time. Interestingly, Chesler and Chesney’s extensive research on many Candlelighters groups of parents of children with cancer did examine this issue.

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Case Illustration 3

Longevity of Groups of Parents of Children with Cancer

Chesler and colleagues carried out multiple studies over several decades of the Candlelighters national group and its local affiliates. Case Illustration 2 described some of their original study of fifty groups of parents of children with cancer in the early 1980s. What happened to those groups a decade later? How many remained? Which types of groups continued and which ones disbanded? We have some answers to these questions through a study that Chesler and Chesney (1995, p. 65) did ten to twelve years after the first research. In 1993, they were able to locate forty-one of the fifty groups; the remaining nine had disbanded (these had been small, independent parent groups, some of which had been failing or had had low levels of activity). The forty-one groups were asked if they were new or the same as in the 1980s: 80 percent of groups said they were the same, while eight groups (20 percent) regarded themselves as new with few or no links to the past. “This is a remarkable degree of historic continuity for local voluntary organizations,” Chesler and Chesney noted (1995, p. 267).

Interestingly, within the types of groups found in 1984, there were changes in leadership over the decade: The professionally led support groups were the most stable, with seven of twelve groups (58 percent) maintaining that leadership, while the other five that had originally been support groups had become SHGs (*n* = 3) or hybrid groups (*n* = 2; Chesler & Chesney, 1995, p. 284). Among SHGs, ten out of nineteen (53 percent) remained SHGs in 1993, while five had become hybrid groups, and four had turned into support groups (p. 284). Hybrid groups were least stable over time, as only 20 percent (two out of ten remained hybrids; five (50 percent) had become SHGs, and three (30 percent) had morphed into support groups (p. 284). This is the only data on changes in leadership and structure over a decade that I’ve seen about SHGs with the same focal issue.

However, the total population of groups in 1993 showed extensive stability in many ways as local voluntary associations. There was the same proportion of professionally led support groups, SHGs, and hybrid parent-and-professional shared leadership groups as in 1981. As before, the SHGs and hybrid groups were more likely to be more formally organized with slightly larger budgets, to conduct business meetings and substantial fundraising, and to include parents of deceased children as members (Chesler & Chesney, 1995, p. 284). Formalization is explicitly and legally required for fundraising from public sources (Chesler & Chesney, 1995, p. 279).

Changes were seen over the decade, especially in the groups’ better relationships with medical professionals and treatment centers, and in changing needs as medical staff offered more psychosocial support services and seemed more aware of parents and their children’s nonmedical needs. Further, local groups received greater assistance from the national-level Candlelighters Childhood Cancer Foundation, which, by 1993, had more staff, a larger budget to serve local chapters, ombudspersons to help families and local chapters advocate for individual rights, and other resources (Chesler & Chesney, 1995, p. 288). The groups’ basic activities remained similar, probably because the stresses and coping that families and their children had facing cancer were similar (p. 287). Chesler and Chesney summarize:

The emphasis on experiential knowledge, on shared life experiences, on providing affirmation and support to one another, on sharing coping styles, and on taking empowered action remain the basic themes of self-help. These resources and strategies cannot be duplicated by professionals. They continue to be the core “magic” of the self-help process and the fundamental underpinnings of all of the activities and operating structures established by local groups. (1995, p. 289)

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Many small unaffiliated groups evolve into formalized nonprofit organizations. Unfortunately, it is difficult to know how many stay as local informal groups or disband after some time versus how many convert to formalized structures; and, more importantly, of those that become formalized, how many lose their member ownership and become controlled by professionals. Archibald’s (2007) important research on SHOs (not SHGs) from 1955 to 2000 studied how they arose, lasted, or disbanded, and is based on a population of formalized nonprofit SHOs because they are available in public records—he found them in the *Encyclopedia of associations* and cross-checked them with B. J. White and Madara’s (2002) extensive national computerized database of SHGs. He is aware that some may have retained the self-help label while having been converted to professionally controlled organizations, but he had no way of determining it. Table 2 shows the number of active national-level formalized self-help organizations (SHOs) by decade between 1955 and 2000; keep in mind that each national organization may have hundreds, if not thousands, of local SHGs. Unfortunately, there are no equivalent databases on the prevalence of informal SHGs in any time period.

Insert Table 2 about here

By the 1980s and 1990s, social and economic forces were bringing about many changes:

(1) Physicians had lost power and influence to the federal government (which had become more involved in health care for seniors, military, the poor, and children) and to other politically powerful players such as the larger number of health insurance companies and increased for-profit mechanisms in health care (White, 1998; Starr, 1982).

(2) An institutional infrastructure to encourage, legitimate, research, and educate about self-help/mutual aid had arisen (described in greater detail in the next subsection). Governments were legitimating self-help/mutual aid, such as the US Surgeon General’s hosting of a “Workshop on Self-Help in Public Health” in 1987; a network of over 200 researchers of self-help had been created; there were now self-help clearinghouses to compile information about SHGs and connect groups to the public (see Borck, 1982; Madara, 1986); and academic centers researching SHGs and SHOs also legitimated and assisted SHGs and SHOs.

(3) The disability movement succeeded in the 1990 passage of the Americans with Disabilities Act. The Act required greatly increased access to streets, buildings, and other physical structures for people using wheelchairs, and outlawed discrimination against people with physical or mental disabilities in the workplace. The disability movement regarded the US ADA as the most significant legislation to improve physical accessibility worldwide (Charlton, 1998).

(4) Patient participation in their illnesses and in health care delivery systems had increased. SHGs and SHOs and other forms of patient support had grown tremendously (Cohen & Syme, 1985; Vaux, 1988). Social support research was revealing the many negative health consequences of the lack of positive social support. The patient’s experience of a specific disease or condition changed a great deal between the 1970s and the turn of the century. See Case Illustration 6 to read about Clara’s strikingly different experiences with the health care system when she was first diagnosed with breast cancer in 1979 compared to its reoccurrence about two decades later.

(5) The Canadian government supported the development of self-help/mutual aid groups and their infrastructure in the 1980s, following, in part, the US examples.

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Case Illustration 4

The Canadian Government Supports Self-Help/Mutual Aid in the 1980s

During Canada’s process of deinstitutionalizing mental hospitals, Hector Balthazar, a social worker in the Department of National Health and Welfare, was charged with aiding the social integration of the mentally ill who had been released from mental hospitals into the community during the 1970s and 1980s. In visiting various centers to learn what was being done, he was surprised to learn “that many social integration activities were being provided by self-help groups, and many of these were crying for support” (Balthazar, 1990, p. 98).

Hector then recounts how the Canadians held their first national self-help meeting in 1982—government officials, academic researchers, and members of self-help groups from Ottawa, Montreal, and Toronto met with Dr. Leonard Borman of the Chicago Self-Help Center, who was invited as a special guest.[[4]](#footnote-4)

Three major initiatives were launched from the 1982 meeting: (1) a book on how to start and sustain a self-help group; (2) a national newsletter, *The Initiative*, appearing in the summer of 1984 (Balthazar, 1990, p. 99); and (3) a film to publicize the movement and educate the general public about self-help groups. A film in French followed (Canada is bilingual) along with curriculum developed for professional schools and promotion of self-help clearinghouses (Balthazar, 1990, pp. 104–110). As part of the International Conference on Social Welfare in 1984, an ambitious program on self-help/mutual aid was developed in three parts: a self-help fair, five major sessions on self-help topics, and the premiere of the French-language film on self-help. An unanticipated result of the self-help fair was that some self-helpers learned new tips on how to deal with troubling issues by visiting the sixty self-help booths at the fair (Balthazar, 1990, pp. 102–103).

Balthazar acknowledged that the self-help clearinghouses and other US initiatives had been “a major source of inspiration for Canadian initiatives” (Balthazar, 1990, p. 98). And, in particular, he praised the efforts of Ed Madara’s computerized database of groups in New Jersey as an important model (pp. 105–106). The Canadian experience indicated that each self-help community must actively want and support a Clearinghouse and that various models were needed to satisfy different situations (Balthazar, 1990, p. 110). Balthazar also warned of the dangers of Clearinghouses becoming infected with a bureaucratic virus, beginning to control, prejudge, and distance themselves from the groups they were meant to serve.

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With increasing globalization, greater international communication, the breakup of the Soviet Union, and former Soviet countries experimenting with democratization, the 1990s brought more international research and interaction. The Canadian government sponsored the first international conference on self-help in Ottawa in 1992 (see *Self-help and mutual aid groups: International and multicultural perspectives* by Lavoie, Borkman, & Gidron, 1994). The only professional peer-reviewed research journal devoted to self-help and self-care was initiated in 1999 as *The International Journal of Self-Help & Self-Care*, and began to publish articles from all three research traditions: addictions recovery, North American psychosocial, and European psychosocial.

### 2.1.5 Movement 3—How the Ex-Mental Patient Liberation Movement Evolved into the Mental Health Consumer/Survivor Social Movement

The deinstitutionalization of large state mental hospitals in the 1950s and 1960s in the United States (triggered by staggeringly higher costs associated with the development of psychiatric medication) emptied mental hospitals of patients who were now supposed to receive help from new community mental health programs in their local communities. However, the community mental health programs were few and disappointing compared to the expectations created by the rhetoric surrounding them (Shadish, 1984). (As case illustration 4 proceeds, note, again, that the terminology and language of the era is used to convey the meaning of the time and to demonstrate changes in attitudes and behavior societally over time.) Ex-patients found each other in local areas, formed self-help/mutual aid groups, and organized in cities around the country (Bluebird, 2009; Emerick, 1991). Angry and often radical ex-mental patients joined forces to develop a protest movement against involuntary and inhumane treatment by the mental health system. The first such organization known in the United States was the Insane Liberation Front in Portland, Oregon, in 1970; it was followed by similar organizations that revolted against forced treatments such as insulin shock therapy and seclusion during involuntary hospitalization and other inhumane injustices (Zinman, 2009). From the beginning, they had the multiple goals characteristic of mutual help: to improve individual coping with life stresses while also advocating to change the mental health system. They communicated through national newsletters, and, later, conferences.

In 1978, Judi Chamberlin’s landmark book *On our own: Patient-controlled alternatives to the mental health system* was published. Chamberlin, who was often called the “Mother of the movement” (Bluebird, 2009), later noted that self-definition and self-determination were among the major organizing principles: “To mental patients who began to organize, these principles seemed equally valid. Their own perceptions about ‘mental illness’ were diametrically opposed to those of the general public, and even more so to those of mental health professionals. It seemed sensible, therefore, to not let non-patients into ex-patient organizations or to permit them to dictate an organization’s goals” (Chamberlin, 1990, p. 325).

Angry confrontations with officials and other professionals characterized the early days of the movement. Radicals engaged in militant political activism and disrupted professional meetings. Upon goading the federal Community Support Program of the National Institute of Mental Health for representation, they were invited to a new “Alternative” national conference, which provided them with a space for organization and exchange. The Community Support Program went on to sponsor annual Alternative Conferences, which provided funding and space for ex-mental patients to meet, exchange views, and develop advocacy activities.

From the beginning, large differences in perspective and strategy occurred within the movement. In the 1970s and 1980s, the radicals who rejected the psychiatric and medical definitions of mental illness clashed with the moderates, who were willing to work with professionals in the mainstream mental health system and believed they could change it by working within the system. While they all endorsed mutual helping and self-help, their advocacy goals splintered the movement as they clashed over whether to reject the mental health system (the radicals), work beside it (conservatives), or change the mental health system from within (the moderates). The sociologist Robert Emerick conducted a national survey of mental health SHGs in 1988, using known groups and requesting referrals to other groups as well as scouring relevant newsletters and other sources to procure a national sample for his study. He obtained usable data from 104 groups and estimated that there were over 1,000 mental health SHGs nationally. Groups were clustered on the East Coast, West Coast, and upper Midwest. A typical group was two to three years old, had three to four leaders, about thirty-three members, and a budget of about $30,000 a year (Emerick, 1996). His findings showed that the majority of groups had political advocacy goals but were moderate in political orientation (63 percent) and were in contact with and willing to work with professionals. A minority (26 percent) were radical in political orientation, and even fewer (11 percent) were conservative—such as Recovery, Inc. and Emotions Anonymous (Emerick, 1989, 1990, 1991).

Over time, the mental health movement achieved some successes. In 1986, Federal legislation required mental health consumers and family members to be on advisory and planning committees. In 1989, the National Association of State Mental Health Program Directors endorsed the use of mental health consumers in their services. Slowly, ex-patients were added to professional committees, consulted about research on consumer/survivors, and included in other mental health system venues. Between 1989 and 2002, the US Substance Abuse and Mental Health Services Administration funded fourteen demonstration projects of peer-run projects, eight of which were described by the peers who ran and researched them in the book *On our own, together* (Clay, 2005). Mental health consumers from eight states were involved in planning and advising the research and implementation of the demonstration projects. Programs were classified in three clusters as drop-in centers, peer support and mentoring, or education and advocacy. I list here the states in which the programs were located along with program founding years, organized by type of project: Drop-in Centers (California 1992, Maine 1981, Missouri 1996, Florida 1992); Peer Support and Mentoring (GROW in Illinois 1978, Pennsylvania 1989); and Education and Advocacy (Connecticut 1994, Tennessee 1995). Note that the majority (five of the eight) were founded in the 1990s. The name of “ex-mental patients’ liberation” gradually changed to become the “mental health consumer/survivor” social movement.

As consumer/survivors began developing and running their own programs, the issue of programs and the possibilities of recovery arose. In general, the advocacy orientation, general hopelessness about recovery from severe and persistent mental illness, and the lack of scientific evidence that recovery was feasible meant that there was a lack of interest in personal recovery until the 1980s. Recovery, Inc. (now known as Recovery International) was almost alone in the mental health area in believing recovery was possible.

Since the 1930s, for Recovery, Inc. members, recovery had meant becoming a productive citizen who could overcome their “nervous” symptoms; work productively; develop a network of family and friends; and develop viable identities other than that of “mental patient” while continuing involvement with psychiatric services. Very similarly to AA, the SHG’s philosophy, worldview, or *meaning perspective* included: (1) a complex program of personal change, which for Recovery, Inc. was set out in the founder’s book, *Mental health through will-training* (Low, 1966); (2) social technology to effectuate change, which I’ve called the *sharing circle*, a dedicated time to exchange experiential knowledge and learn how to apply the program to their daily lives; and (3) mutual helping roles so that members became help givers as well as help seekers.

The mental health movement originally accepted the sharing of personal experience in SHG sharing circles and the intense work on personal change and coping. Over time, however, interest in the sharing circle and personal change activities decreased for some activists as they focused more on political action. While some lost interest or were merely uninterested, some became actually antagonistic, making claims to understanding mutual helping and self-help/mutual aid when they did not (Borkman, Karlsson, et al., 2005; R. Hollman, personal communication, January 5, 2019). For some, the outward advocacy orientation kept them from facing their own mental health issues or taking responsibility for dealing with them (Leete, 1993).

As consumer/survivor confidence grew through their experiences running consumer-run programs, and as scientific evidence of the feasibility of recovery from serious and persistent mental illness accumulated, the mental health consumer/survivor movement added recovery as a secondary goal in the 1990s—at least two decades after the movement started. Their understanding and development of recovery and their technologies of recovery, accordingly, are divergent from those in AA and the other social movements. In the mental health consumer/survivor movement, the 1990s became known as the “Decade of Recovery” (Anthony, 1993). Mental health consumers who also had medical degrees or PhDs developed visions of recovery for the persistent and seriously mentally ill, which, along with a multitude of epidemiological studies, demonstrated that this previously seemingly hopeless group could in fact recover and have a productive life while managing their symptoms (Anthony, 1993; Fisher & Spiro, 2010). Leaders of the mental health recovery movement described the shift in thinking of many mental health consumer/survivors as going from considering themselves “the object of neuro-chemical forces to being empowered agents who are finding the freedom to begin to creatively and effectively run our own lives. This paradigm has emerged through self-help groups in which mental health consumer/survivors have been sharing our lived experiences of personal recovery” (Fisher & Spiro, 2010, p. 214).[[5]](#footnote-5)

Advocates pushed for and succeeded in the development and funding of various kinds of mental health peer- or consumer-run organizations (CROs), the most prevalent of which were referred to as “drop-in centers.” These were funded by state and local governments and usually designed with oversight by mental health professionals and some mental health consumer input. This funding required them to incorporate as legal tax-exempt nonprofit organizations. Given the government’s control through its funds, the CRO literature is relatively silent about the possibility of co-optation or manipulation by funders, with a few exceptions (see Borkman & Karlsson, 2005; L. D. Brown, Wituk, & Meissen, 2010). By 1993, forty-six of fifty states had funded 567 mental health consumer-run initiatives (Segal, Silverman, & Temkin, 1993).

With the maturation and success of the movement around the year 2000, individuals and groups considered various ways of describing themselves and agreed on naming themselves “mental health consumers” or “consumer/survivors” (Fisher & Spiro, 2010). (In Europe the mental health patients prefer to use the term “service-users.”) After recovery from severe mental illness became a commonly adopted goal, many CROs changed their name from “Drop-In Center” to “Wellness and Recovery Center.” Many states and local governments fund consumer-run drop-in centers, wellness centers, or other peer-run initiatives.

By the end of the 1990s, academic community psychologists were characterizing the emerging paradigm as empowerment and community integration (see Nelson, Lord, & Ochocka, 2001). In Ontario, Canada, a province-wide set of community-based, interconnected CROs and peer-run projects with government support were the most far-reaching and innovative project (Nelson, Lord, & Ochocka, 2001). The Canadians envisioned and began integrating mental health consumer/survivors into all aspects of the province-wide mental health system, including policy, research, leadership, and services. Somewhat similar ideas were seen in the United States with the president’s New Freedom Commission on Mental Health (2003), but ultimately were not implemented as set out.

A US national survey of mental health self-help groups, consumer-run service organizations, and advocacy organizations was completed in 2002 (Goldstrom et al., 2006). The premier federal surveying agency, the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration, which regularly surveys all professionally based psychiatric agencies, psychiatric units in general hospitals, and mental hospitals, had conducted its first statistical sampling of mental health SHGs and CROs. They enlisted thirty self-identified mental health consumers and family members belonging to such groups to advise them in the planning and conducting of the survey. The survey excluded organizations run by professionals, such as therapy groups, lodges, and clubhouses; groups dealing with substance abuse; internet groups; and groups for life crises such as bereavement, transitions, family problems, or victimization; but included groups for family members such as the large and politically powerful National Alliance on Mental Illness. The researchers said the sampling universe consisted of likely participants from the 5.4 percent of the population diagnosed as having serious mental health problems, their families, and the families of the 9–13 percent of youth and children with severe emotional disturbance. Using sophisticated sampling design from the National Comorbidity Study, their sampling frame of 172 counties in thirty-four states represented the entire country, from which they collected data on all the groups and organizations found there. From this statistical design they obtained estimates of the national numbers of mental health SHGs, consumer-run services, and self-help advocacy organizations. Table 3 shows the survey’s nationwide estimates of the number and percentage of each of the three types of self-help organizations and their estimated number of attendees.

Insert Table 3 about here

As seen in Table 3, while there are more SHGs (44 percent) than any other type of organization, they had the smallest number of attendees or members. The self-help advocacy organizations had many more members (over 1 million) than either of the other types. The survey provided a list of activities and asked each group or organization to identify which activities they offered. Unfortunately, they did not offer a category for hosting a sharing circle or the equivalent on the list of activities, so the reader cannot identify how many CROs and self-help advocacy organizations hosted sharing circles or SHG meetings; the SHGs’ major activity was the sharing circle, which was indicated by the way they defined their “primary purpose” as being “to attend mutual support group meetings” (Goldstrom et al., 2006, p. 95). A majority of all three types of groups and organizations offered telephone support and social and recreational opportunities. The CROs and self-help advocacy organizations offered a wide range of activities, such as providing advocacy and rights protection, distributing others’ information, arts activities, and mentoring or buddy systems. The CROs were most likely to operate a drop-in center (63 percent) (Goldstrom et al., 2006, p. 97).

Despite starting out as angry advocates for major changes to the mainstream mental health system fifty years ago, the movement has evolved into a partnership and collaboration with the system; the survey found that less than 1 percent view their participants’ work and services as substitutes for professional help. Strikingly, the total combined figure of 7,467 self-help peer-based groups, advocacy organizations, and CROs greatly exceeded the number of professionally based traditional mental health organizations in the United States (*n* = 4,546). The researchers concluded that “mental health self-help has evolved from its de facto status into the mainstream of the mental health service delivery system” (Goldstrom et al., 2006, pp. 99–100).

State-based certified training programs have been developed for mental health consumers to become peer support specialists (or other positions with similar titles), the salaries for which are reimbursable by the federal or state health insurance such as Medicaid. An increasing number of such peer support specialists are paid employees in CROs or professionally based mental health agencies. By 2006, thirty-one states had statewide consumer/survivor advocacy organizations. The US Substance Abuse and Mental Health Services Administration, in a signal of acceptance and legitimation, listed consumer-run organizations as an evidence-based practice in 2009. By 2014, thirty-six states had peer support specialist jobs for which they could bill Medicaid insurance for reimbursement (Myrick & del Vecchio, 2016).

The ex-mental patient liberation movement, now mental health consumer/survivor group movement, is a more conventional form of social movement, as the groups have been intensely political—even confrontational, in their early days—and they have evolved a unified national-level coalition organization of statewide consumer/survivor organizations (Fisher & Spiro, 2010). The mainstream mental health system began changing to accommodate the extent, forcefulness, and determination of the consumer/survivor movement, and to accommodate the consumer/survivor/patient-centered recovery framework. The substance use addictions and mental health concepts of recovery have started to be consolidated as behavioral health units in the public mental health system, but professional bureaucracies require drastic changes to adapt to client-run recovery where professionals are support staff instead of experts. Thus, real changes in professionally based systems have been slow to occur (see Gagne, White, & Anthony, 2007; Nelson, Kloos, & Ornelas, 2014). “Peer” became increasingly used as a synonym for consumer/survivor, although both terms were widely used by policy makers and in the literature. Community psychologists created a more compelling paradigm of community mental health, suggesting that transformative change was occurring in the system and in the basic manner with which individuals with mental health conditions were regarded; first and foremost, the person with mental health issues should be regarded as a citizen with the same legal rights as all others (Nelson, Kloos, & Ornelas, 2014).

### 2.1.6 Summary of Similarities and Differences across the Three Social Movements

This subsection summarizes the major similarities and differences across the three social movements. Major similarities were characterized earlier as an ethos or the 14 values and principles held in common, listed in Subsection 2.1.1 (Katz & Bender, 1976b; F. Riessman, 1997). Additional similarities have been (1) a major social technology—the sharing circle, which uses personal lived experience as authoritative knowledge and the surrounding personal relationships as support; and (2) the original small-group structure of organization, which is named an SHG (self-help group). Many groups evolved into more formalized organizations such as incorporated tax-exempt 501(c)(3)s, which have been referred to here as nonprofit self-help organizations (SHOs).

Major differences found between the three social movements according to my analysis are shown in Table 4.

Insert Table 4 about here

As seen in Table 4, key differences across the three movements stem from the originating societal reaction to the health or social condition and the group’s response: Alcoholics developed a recovery-based small-group structure that is relatively impervious to bureaucratization or professionalization, with no advocacy goals, while the ex-mental patients emphasized (1) primarily, advocacy goals to eventually establish government-funded formalized organizations that they operated and to change the mainstream mental health system from within; and (2) secondarily, personal coping goals that became recovery goals in the 1990s and later. The general self-help/mutual aid group movement was extremely diverse in goals, organizational structures, and relationships with mainstream services. SHGs focused on their own illness or social condition silo and were largely indifferent to a more general self-help/mutual aid movement.

The next subsection discusses the infrastructure supporting SHGs and SHOs that evolved in the 1950s through the 20th century—one that consisted of maverick professionals who became “self-help supporters,” self-help resources and clearinghouses that connected SHGs to the public and professionals, and public policy and government support.

## 2.2 Infrastructure in Support of Self-Help/Mutual Aid

Groups and organizations need infrastructure support (followers or members, resources, legitimation from their environment) to exist and persist. Major sources of this infrastructure are professional support, systemic organizational support, public policy, and governmental actions. Social movement organizations that challenge existing ideologies, as self-help groups did in the 1970s and 1980s, especially need bolstering to counter resistance from status quo organizations and professionals. The paradox is that the SHGs challenged the very professionals and health and welfare institutions that also supported and legitimized them. Chronologically speaking, maverick professional practitioners and academics helped initiate SHGs, supporting them through the development of self-help clearinghouses and resource centers before there was much public policy and governmental support. In the process, these maverick practitioners and academics helped legitimize SHGs.

This section describes the infrastructure that developed to legitimize and support self-help/mutual aid by focusing on the maverick professional practitioners and academics who assisted and researched SHGs—we know of them primarily through their publications—and by discussing the systemic organizational support (public policy and governmental support) that developed.

### 2.2.1 Maverick Professional Support and Legitimation

As a researcher in the 1970s, I witnessed SHGs’ challenges and opposition to mainstream professionals but found those challenges confusing, ambiguous, and paradoxical. For example, in my research on an SHG for people who stutter, I saw self-helpers repeatedly criticize speech therapists and the inadequacies of various kinds of speech therapy while they simultaneously used specific speech therapies in selective ways (Borkman, 1999a).[[6]](#footnote-6) Other researchers in the 1970s observed the opposition of SHGs to professionals and noted the paradoxical behavior, but the researchers’ explanations were general or vague (Gartner & Riessman, 1976b; Steinman & Traunstein, 1976). Not until the sociologist Matthew Archibald’s brilliant book, *The evolution of self-help: How a health movement became an institution* (2007), did the paradox become clear. Archibald explained the process of legitimation with specific case studies as well as quantitative analyses of a large data set of self-help organizations. It took forty years and the institutionalization of SHGs to finally unlock the puzzle.

Archibald spoke of four major sources of legitimation of SHOs: physicians (measured through articles in medical journals), academia (measured as social science research publications), popular press (measured through articles in *The New York Times*), and the political sphere (measured through congressional testimony). Different kinds of SHGs were dependent on different sources of legitimation. I was struck by the fact that social science research was apparently one major source of legitimation, but that it also contributed to articles in *The New York Times*, which prominently features social science research when describing new social phenomena, and to congressional testimony, which often combines research findings with personal testimonies.

Some maverick professionals (practitioners and academics), critical of the narrowness of their discipline’s paradigms or the ineffectiveness of therapies, assisted in the founding and development of some major self-help groups (e.g., Borman, 1979). Other maverick academic researchers evolved networks to study self-help groups, and in some cases also developed self-help clearinghouses or databases about them, in order to connect the public with groups and to assist groups in sustaining themselves (e.g., Farquharson, 1995). Ten of the leading maverick professionals supporting SHGs were interviewed by Farquharson (1995), who noted that “they modeled a deep respect for the capacity of people to exchange help and support, and were alert to the limitations of professional helping” (p. 83). Farquharson found that maverick professionals characterized themselves as “innovators who functioned on the margins of their discipline” (p. 84). They thought that as mutual aid gained legitimacy over time, they “earned more mainstream acceptance” (p. 85). They also reported changing their approaches to their work as a result of learning about self-help/mutual aid processes, which included giving clients or students more choices and more opportunities for experiential learning.

Leonard Borman, himself a maverick anthropologist who created a team of researchers with Morton Lieberman and others, researched the origins and development of ten major self-help groups that started between 1935 and 1975 for various disorders, and found that all but two were founded with professional assistance. Borman (1979) looked at AA and Synanon, for addictions; Recovery, Inc. and GROW, for mental health issues; Compassionate Friends, for parents losing a child; Parents Anonymous, a preventive group for abusive parents; NAIM, a Chicago group for the widowed founded under the auspices of the Catholic Church; Integrity groups for lost souls, helping primarily university-trained professionals to find their compass; Mended Hearts, for heart disease; and Epilepsy Self-Help. Professionals had founded or co-founded all but Synanon and NAIM. Five (AA, NAIM, Synanon, Compassionate Friends, and Epilepsy Self-Help) had received significant help from professional supporters (Borman, 1979). Today, forty years later, many of these remain viable organizations.

Social science researchers “discovered” self-help groups between 1975 and 1980, during which observers “have described the proliferation of such groups as a veritable explosion, sprouting like mushrooms after a rain” (Borman, 1975b, p. 333). This growing and intriguing phenomenon of SHGs was considered extensively in several books, special issues of journals, and a number of conference proceedings. Previously, research interest in contemporary self-help/mutual aid had been sparse and sporadic. Anthropologist Leonard Borman spearheaded an early conference in 1974, funded by the W. Clement & Jessie V. Stone Foundation, whose proceedings were published as *Explorations in self-help and mutual aid* (Borman, 1975a). Invitations were made to fifty leader-members and members of SHGs, researchers, educators, and policy makers to consider how to help SHGs learn from each other, increase their visibility with the public, improve research and training about them, and explore their implications for public policy (Borman, 1975a, pp. ii–iii). Self-help/mutual aid was viewed broadly as including the independent and autonomous self-help/mutual aid efforts of small groups (such as AA; Recovery, Inc.; Mended Hearts; and Integrity groups), residential or geographic communities (such as Synanon, Delancey Street, and Homecoming housing run by ex-mental patients), and the American Indian Ecumenical Conference.

Social psychologists Alan Gartner and Frank Riessman edited *Self-help and health: A report* (1976b), which described a conference hosted by the New Human Services Institute of Queens College at the City University of New York in 1976, then published a book titled *Self-help in the human services* in 1977. The Self-Help and Health Conference (Gartner & Riessman, 1976b) focused on how self-help groups were composed of participating members who wanted to be involved in their health care and deal with the focal issue of concern to the group. This is congruent with the changing epidemiology where chronic disease had become more prevalent as infectious and communicable diseases had come under control. Other issues, such as appropriate professional involvement in an SHG and when professionals help or hinder groups, were recurring themes in the conference report, as was the usefulness of SHGs for chronic illness care, such as that for kidney transplant patients. Gartner and Riessman’s book (1977) critiqued the professional model of human service, noting that professional control and exclusiveness had become excessive, often slighting client needs. Radically at the time, they stated that human services should be centered on the client (p. 13), not subordinated as they were in the professional-dominated model. They contrast “professional” with the term “aprofessional” to describe peers who help each other. “Aprofessional” is seen as intuitive, concrete, experiential, and subjective in contrast to “professional,” which connotes distance, perspective, reflection, systematic knowledge, and understanding (Gartner & Riessman, 1977, p. 14). “Aprofessional” is an unfortunate term, as it keeps “professional” as the basis of the relationship rather than using a term that implies that the “client” has a distinctly different relationship to the help giver than to the professional.

Special issues of *The Journal of Applied Behavioral Science* (*JABS*) and *Social Policy* were devoted to self-help groups in 1976 (Lieberman & Borman, 1976b; F. Riessman, 1976). *JABS* was edited by Morton Lieberman, who teamed up with Leonard Borman for the special issue (Lieberman & Borman, 1976b), which included most researchers from the 1975 Explorations conference such as Levy (1976), Tracy and Gussow (1976), and O. Hobart Mowrer and Anthony Vattano (1976). The purpose of *JABS* special issue was to examine SHGs from the perspective of social science and to discover what each could learn from the other.

Social workers Alfred Katz and Eugene Bender wrote and edited *The strength in us: Self-help groups in the modern world* (1976b), which became especially well known; they were intrigued by how SHGs were becoming vehicles by which outcast persons could develop new identities by creating alternative strategies and structures in society. SHGs, which they considered unusual revolutionaries, were not interested in a classical transfer of power but in the development of social competencies and relationships and changing societal attitudes and institutions (pp. 5–6). “We view the current groups as bringing into being distinctive and new forms of egalitarian social relationships,” Katz and Bender wrote (p. 8).

My paper describing experiential knowledge as a distinctive characteristic of self-help groups was also published then in *Social Services Review* (Borkman, 1976a). Durman (1976) referenced it in the *JABS* special issue, picking up on the point that self-help groups were not anti-professional, but rather preferred using their own experiential knowledge and investing more authority in it.

Psychiatrist Gerald Caplan and Marie Killilea edited *Support systems and mutual help: Multidisciplinary explorations* in 1976, which was a somewhat different mix of descriptions of autonomous self-help groups such as Recovery, Inc. alongside professionally guided mutual aid efforts organized by the Harvard Medical School Laboratory of Community Psychiatry. The Widow-to-Widow program paired a widow’s aide—a widow who had been through her grief and found a new identity—with a new widow who needed support and understanding. This program was later accompanied by a hotline telephone service called the Widow Service Hotline, staffed by volunteers from the Widow-to-Widow program and supervised by widow aides (Gartner & Riessman, 1977, pp. 58–59). Phyllis Silverman, also at the Harvard Laboratory of Community Psychiatry, wrote a monograph jointly published by the National Institute of Mental Health and the US Department of Health, Education, and Welfare in 1978, titled *Mutual help groups: A guide for mental health workers*.

These important publications highlight the work of what I came to recognize were six networks of then-maverick professionals—practitioners and academics—who shaped the significant perspectives of SHGs and SHOs; they also created self-help clearinghouses or resource centers to support and legitimize them publicly. These networks became the backbone of the early North American psychosocial research tradition. Several characteristics are noteworthy: Atypically for the time, these maverick professionals came from different disciplines and worked together—for example, anthropologist with psychologist, such as Borman and Lieberman. Most of the maverick interdisciplinary professionals, including myself, both conducted research and engaged with the SHGs they studied, which is typical in disciplines such as social work and psychology, but was unusual then in anthropology and sociology. Each network’s distinctive contribution will be briefly highlighted to give the reader the flavor and variety of contributions.[[7]](#footnote-7)

(1) Alfred Katz and colleagues at the University of California, Los Angeles (UCLA): Alfred Katz was a major figure in SHG research. For his doctoral dissertation, he studied four parent-run groups of parents with handicapped children; within 5 years, all but one had evolved into a professionally led and professionally controlled organization (Katz, 1961). Katz and Bender’s (1976, p. 9) early definition of self-help groups is widely used. The California Self-Help Clearinghouse was at UCLA. Katz, a prolific researcher, led efforts to publicize and connect international research from Europe and Asia with the United States—he chaired an early international conference on self-help/mutual aid in Dubrovnik, Croatia (Katz, 1984). He co-founded and co-edited, until his death, the only journal exclusively devoted to self-help, titled *The International Journal of Self-Help & Self Care*,which was published from 1999 to 2014*.*

(2) Leonard Borman at Northwestern University in Chicago and Morton Lieberman at the University of Chicago, later in San Francisco: Borman was a prolific researcher and champion of SHGs from 1975 through the mid-1980s, and he initiated one of the first self-help clearinghouses in 1974. Unfortunately, he died prematurely. He was one of the few behavioral scientists attuned to the issue of how SHGs obtain legitimacy (Lieberman & Borman, 1979). He consulted with the Canadian government in 1982, assisting them in deciding how to support self-help/mutual aid (see Case Illustration 4). His colleague Morton Lieberman was the rare psychologist (and rigorous methodologist) who did appropriate experiments on self-help initiatives, such as using a waitlisted group of seniors who wanted to obtain training in the Senior Actualizations and Growth Explorations (SAGE) initiative as a control group (Bliwise & Lieberman, 1984).

(3) Frank Riessman and Alan Gartner at the City University of New York Graduate Center, Co-Directors of the National Self-Help Clearinghouse: Riessman and Gartner were a team for many years until Gartner turned to other research. Riessman is best known for his concept of the “helper” therapy principle (1965) which states that those who help others gain more by helping than by being helped. The “helper” therapy principle remains a central concept in self-help/mutual aid and peer support today. Riessman is also well known for calling for the restructuring of human services to make all clients helpers or prosumers—that is, a provider and a consumer (Riessman, 1990). Gartner and Riessman co-directed the National Self-Help Clearinghouse in its early years and did many youth and adolescent peer-to-peer projects.

(4) Gerald Caplan, Phyllis Silverman, and colleagues at the Harvard Laboratory of Community Psychiatry: Caplan, a psychiatrist, focused on mutual support. The researchers studied autonomous SHGs but also slightly different versions of peer support. For example, Silverman (1976) described the Widow-to-Widow program that paired a widow’s aide—a widow who had been through her grief and found a new identity—with a recent widow who needed support and understanding. Along with general discussions of the family as a support system and the incidence of religious ideas in self-help groups, the volume *Support systems and mutual help*,edited byCaplan and Marie Killilea (1976), included the most thorough review of interpretations of self-help and mutual aid (Killilea, 1976).

(5) Leon Levy and colleagues at the University of Maryland: Levy was a well-known community psychologist with special expertise as a methodologist. Among other things, he contributed a major classification of four types of groups based on their purposes and composition (1976, pp. 312–313) that was widely used by other researchers: (a) conduct reorganization or behavioral control (e.g., AA), (b) share a common status that entails some stress (e.g., Recovery, Inc.; Parents Without Partners), (c) survival-oriented—hold some stigmatized or deviant status (e.g., gay pride, women’s consciousness-raising groups), or (d) share a common goal of personal growth and self-actualization (e.g., Integrity groups). His colleagues included Richard Wollert and Ken Maton, who also did important work separately (e.g., Maton, 1988, 1993; Wollert & Barron, 1983).

(6) Richard Wollert and colleagues at the University of Portland in Oregon: Wollert and colleagues worked with other researchers such as Leon Levy (Wollert, Levy, & Knight, 1982). Wollert and colleagues in Oregon developed a self-help resource center that was unusual in being integrated with a local social referral center (Wollert & Barron, 1983); they also researched unusual self-help groups such as Parents United for sexually abusive families (Wollert, Barron, & Bob, 1982) when the criminal justice system and other professionals were separating families from the abuser.

Gradually over time into the 1990s, as SHGs became more acceptable and understood, the researchers studying them became less maverick and more mainstream. Detailed below are additional networks of academic researchers and practitioners in the 1980s to 1990s who contributed to the infrastructure for self-help/mutual aid or assisted spinoffs and offshoots. They were all “self-help supporters” (Oka & Borkman, 2011) who understood and appreciated self-help/mutual aid on its own terms.

(1) Greg Meissen and colleagues at Wichita State University in Kansas: A local self-helper, Evelyn Middelstadt, initiated a self-help center at her kitchen table in 1984 and teamed up with Professor Greg Meissen at Wichita State University to co-found The Self-Help Network at the University in 1985 (Archibald, 2007). The Network compiles and maintains an up-to-date statewide database of SHGs in Kansas, serving as a source of information for the public and professionals seeking a group and as a resource for research (Meissen & Warren, 1993). Several generations of students have been trained in research at the Network (L. D. Brown & Wituk, 2010; Gaston & Meissen, 1999; Meissen, Gleason, & Embree, 1991; Shepherd et al., 1999), not to mention professors producing important publications from research done there (e.g., Medvene & Teal, 1997; Medvene, Wituk, & Luke, 1999). Noteworthy has been the Center’s capacity for meaningful change with the times. The Self-Help Network was re-envisioned when the emerging trend for SHGs gave way to SHOs and peer support, and more formal community organizations requested services. Renamed the Community Support and Research Center in the mid-2000s, it provided consultation on organizational issues, and became an intermediary organization for the network of about twenty formalized mental health consumer/survivor nonprofit organizations. As an intermediary, the Center gave workshops in formalized nonprofit development, writing grant proposals, and financial work, and trained often inexperienced persons who had serious mental health issues in how to operate their consumer-run organizations. The Center continued to grow and expand in response to requests from community organizations, local governments, and others; in 2015, they reorganized and were renamed the Community Engagement Institute, led by Scott Wituk.

(2) Thomas Powell directed the Self-Help Research and Knowledge Dissemination Center at the University in Michigan, School of Social Work. Among the contributorsi were Linda Farris Kurtz (1997, 2015) and Ernest Kurtz (1979). Several studies focused on severe mental illness (L. F. Kurtz et al., 1995; T. J. Powell et al., 2000). Other contributions include T. J. Powell (1987, 1990a, 1990b, 1994), T. J. Powell & Perron (2010), and T. J. Powell & Kurtz (2016).

Also at the University of Michigan in the Department of Sociology, Mark Chesler (1991), mounted various studies with his students of the Candlelighters, a self-help group for parents of children with cancer (Chesler & Chesney, 1995; Chesler & Yoak, 1984; see Case Illustrations 3 and 4 for details of his work). Chesler (1991), himself a parent of a child with cancer, made meaningful innovations in the application of participatory action research in his work.

(3) Julian Rappaport, colleagues, and students at the University of Illinois at Urbana-Champaign: Rappaport, a community psychologist, and his colleagues and students were trailblazers in establishing long-term collaborative research relationships with an SHG that originated in Australia named GROW, a self-help recovery program for persons with mental health problems patterned partly after AA, using its 12-steps in modified form (Rappaport et al., 1985). Rappaport (1993) also innovated the use of narrative analysis and storytelling to explain key processes in SHGs. His colleagues and students (Kennedy & Humphreys, 1994; Luke, Roberts, & Rappaport, 1993; Roberts et al., 1999; Salem, Reischl, & Randall, 2010) developed instruments tailored to SHGs to measure help-giving and help-receiving processes, among other contributions.

(4) Canadian community psychologists, such as Francine Lavoie at Laval University in Quebec and Geoff Nelson at Wilfrid Laurier University: Canadian community psychologists and government policy makers importantly added international dimensions to self-help/mutual aid. They hosted the first important international conference on general SHGs in 1992, from which a book of research (Lavoie, Borkman, & Gidron, 1994) was produced that was simultaneously published as a double issue of *Prevention in Human Services* (vol. 11, nos. 1–2). In 1994, Canadians hosted an international conference to review the results of an eight-country study of AA (Mäkelä et al., 1996; Ogborne, 1995). Other Canadians contributed to the international dialogue (Fine et al., 1995; Romeder, 1990; Stewart, 1990; Todres, 1995). Geoff Nelson and colleagues created an alternative conceptual framework to explain self-help/mutual aid and peer support in mental health services (Nelson, Lord, & Ochocka, 2001) and assisted in developing province-wide integrated mental health consumer/survivor and mainstream initiatives. They also innovated in participation action methodologies (Nelson et al., 2010).

(5) Leonard Jason, Joseph Ferrari, colleagues, and students at DePaul University in Chicago: Jason, Ferrari, colleagues, and students initiated research on a housing-based spinoff of AA named Oxford Houses in the mid-1990s. They cultivated a notable decades-long research collaboration that provided Oxford House with credentials as an evidence-based practice with the federal agency SAMHSA (Substance Abuse and Mental Health Services Administration) and enabled generations of graduate students to complete significant research and publications (Jason, Olson, & Foli, 2008; Jason, Ferrari, et al., 2006).

### 2.2.2 Systemic Organizational Support and Public Policy

Resource centers and other systemic organizational supports of SHGs and SHOs are important to their birth, growth, and survival: “In general, by emphasizing peer support and relying on their own members for legitimacy, self-help groups are less dependent on external resources, except for the recruitment of members. … Self-help groups that promote information, education, and referral services are more dependent on external resources” (Hasenfeld & Gidron, 1993, p. 223). The self-help literature recognized the importance of systemic organizational support (Lieberman & Borman, 1979; Silverman, 1992) and suggested six ways that external organizational resources could assist SHGs and SHOs: (1) a source of members by bringing together new people to form a new group or join an existing group; (2) provide guidelines for organizing meetings and structuring group activities; (3) provide workable *meaning perspectives* (Borkman, 1999a) or worldviews (Kennedy & Humphreys, 1994) on how to define and cope with the focal problem; (4) provide consultation & training for members who want to become leaders and helpers (Silverman, 1992); (5) give encouragement and support to reduce SHG members’ sense of isolation and increase confidence (Madara, 1986); and (6) provide tangible resources such as meeting places or publications.

This subsection discusses two kinds of resource centers: national self-help organizations, which serve local units of a SHG for one issue, and self-help clearinghouses, which serve almost all SHGs in a specified area. Other systemic supports such as various health and human service agencies and community organizations can be important, but are only occasionally mentioned. A case study I did in 1995 comparing self-help clearinghouses in their governmental and social policy contexts in the United States and Canada is described; this is a one-of-a-kind analysis in the self-help literature. Finally, the federal government support in the United States for self-help mutual aid is discussed.

National self-help organizationsare formalized organizations that serve all the local units of one specific kind of SHG; they developed as an alternative to self-help clearinghouses. AA, for example, created a national tax-exempt formalized nonprofit organization in New York City early in its development that controlled the copyrights and publishing of their official literature, advised local groups on procedures, helped them troubleshoot group challenges, and informed the public and professionals about how to access meetings and how meetings worked (E. Kurtz, 1979). Analysts have hypothesized that local SHGs without affiliations with a national SHO or local community agency are less viable in the long run than SHGs that have such affiliations. In a study of New Jersey using the New Jersey Self-Help Clearinghouse database, comparing birth and death rates of SHGs over an eighteen-month period in 1983–1984, researchers found that local unaffiliated groups initiated new groups much faster than affiliated ones; AA groups, which were analyzed separately because they were so numerous, were found to have a much lower mortality rate than other kinds of groups (Leventhal, Maton, & Madara, 1988). Affiliated groups connected to a national organization were 90.1 percent of the total 2,950 groups in 1984 (Leventhal, Maton, & Madara, 1988, p. 598). T. J. Powell (1990a) also argued that affiliated organizations were more stable and long-lasting than local unaffiliated ones because of the built-in resources and help that come with affiliation. One study by Gaston and Meissen (1999) found that a statewide SHO for the National Alliance on Mental Illness provided important benefits to the twenty-three local units by its efforts to lobby for changes on state and national level, and informing local units of up-to-date changes nationally.

Self-help clearinghousesbecame an important intermediary, providing information about SHGs to the public, assisting SHGs in their formation, and assisting their efforts to inform the public, recruit members, and become sustainable. They were initiated in various places independently in the 1970s and 1980s, flourished in the 1990s, then largely succumbed to internet technology and changing practices after 2000. Clearinghouses were never fully legitimized and had difficulties obtaining funds and resources (Hedrick, Isenberg, & Martini, 1992; T. J. Powell, 1994). The meaning of the term “clearinghouse” and its functions were unclear to many citizens (Fine et al., 1995, p. 120) Few governments funded them; some were maintained primarily by volunteers. The one exception is Germany, which developed a nationwide network of advice centers that were funded by legally mandated public health insurance monies (see Matzat, 2006; and Munn-Giddings & Boyce in Section 4 of this article).

The literature on self-help clearinghouses (hereafter Clearinghouses) is sparse and discontinuous. There are case studies of individual Clearinghouses but few surveys of the entire landscape. Leonard Borman started the first Center in Illinois in 1974; others followed in the 1980s—especially noteworthy were the statewide New Jersey Self-Help Clearinghouse (founded in 1981) and the National Self-Help Clearinghouse in New York City (Gartner & Riessman, 1984). A 1984 survey of nine regional Centers included the above three as well as Centers in California, Texas, Oregon, Connecticut, Kansas, and Nebraska. The New Jersey Self-Help Clearinghouse (also named the American Self-Help Clearinghouse) created a nationwide computerized database of SHGs and SHOs under its director Edward Madara that was a national resource; they also published at least twenty-four editions of *The Self-Help Support Group Directory*, which had a database of information about 6,700 groups in New Jersey and over 1,000 national organizations, one-of-a-kind group models, and online groups (Broderick & Rodenbaugh, 2009, p. 8). In 1988, fifty Clearinghouses were found in various states and cities, but only twelve years later they had begun to dwindle in number. Some Clearinghouses—usually associated with universities—conducted research on SHGs. These included Kansas’s Self-Help Network; the Portland, Oregon Center; the American Self-Help Clearinghouse; and the National Self-Help Clearinghouse in New York City.

In Canada, a similar pattern of developing self-help clearinghouses occurred, except a little later. Todres (1995) surveyed seventeen Centers found in fifteen cities and seven of ten provinces in 1995. A major freestanding Center found in metropolitan Toronto was described in Fine et al. (1995). Although funding of Clearinghouses by government was spotty and tenuous, Canadian ones may have fared better than US Clearinghouses, as the health policy in Canada explicitly included self-help/mutual aid, which greatly legitimized it in comparison to how it was treated in US health policy (T. J. Powell, 1994), as described in Case Illustration 5.

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Case Illustration 5

Self-Help Resource Centers in the United States and Canada in Relation to Health Policy

In 1995, I received a Fulbright research fellowship to study model Centers in the United States and Canada and in relation to health policy. This was at the height of Centers’ activities and influence and also the only such comparison available. I studied the Resource Centre of Metropolitan Toronto in Ontario province in Canada and the statewide resource center named the Self-Help Network in Wichita, Kansas. This case illustration is based on materials from that study (see Borkman, 1996a, 1996b).

The two Centers were selected because of their similarities and my access to them. They were both legally incorporated nonprofit Centers about ten years old with similar primary goals, staffs of eight to eleven part-time and full-time persons, and substantial budgets funded by multiple sources. Their primary goals were to maintain databases of SHGs, to connect the public with the SHGs, and to assist the formation of new SHGs and sustainability of established ones. Their major differences were that Metro Toronto was a freestanding unit while the Self-Help Network was affiliated with Wichita State University, from which it received some legitimacy and in-kind resources.

A mixed-methods approach involved observing Metro Toronto’s activities for four months in Canada, interviewing sixty-five leaders, officials, providers, and self-helpers, and analyzing archival materials. I volunteered one day a week at the Centre, which was an excellent way to gain inside information and establish contact with SHGs and potential interviewees. In the United States I observed the Self-Help Network for one month and interviewed thirty-nine people in similar roles. I needed less time and fewer interviews since I was so familiar with the US scene and had established relationships with some of the principals.

The United States and Canada make for an interesting comparison because they have many similarities; they differ, however, in values, government, and health and welfare institutions. Seymour Martin Lipset’s *The continental divide* (1989) identified important value and institutional differences based partly on each country’s history. While revolutionaries broke away from England to form the United States, Canada maintained loyalty to the British crown. The US Constitution offers life, liberty, and the pursuit of happiness, whereas Canada’s constitution offers peace, order, and good government. Lipset characterized Canada as being “more class-aware, elitist, law-abiding, statist, collectivity-oriented and particularistic (group-oriented) than the United States … [with resulting] variations in literature, religious traditions, political and legal institutions, and socioeconomic structures” (1989, p. 8). Canada has a single-payer national health insurance system, whereas US health services are characterized by sociologists as a nonsystem since it was so ad hoc, fragmented, left out so many people, and was expensive, funded by various private and public sources (Cockerham, 2002). In 1995, both countries faced huge financial deficits that were resulting in major changes, including decreased governmental support of health and welfare systems.

The growth and diversity of self-help/mutual aid seemed to be roughly similar in the United States and Canada, and there were many ways they functioned as an integrated unit. Alcoholics Anonymous, for example, included US and Canadian groups together in its governing structure and statistics (E. Kurtz, 1979). Canadian academics participated in major US professional associations such as ARNOVA (Association for Research on Nonprofit Organizations and Voluntary Action) and SCRA (Society for Community Research and Action), which were both major interdisciplinary associations that featured research on self-help/mutual aid, especially in the 1980s and 1990s, at their respective annual and biennial conferences in Canada and in the United States. National representative sample surveys in that time period found roughly similar estimates of the use of SHGs by US and Canadian citizens—approximately 3.0–3.8 percent of the US population (Wuthnow, 1994) and about 2 percent of the Canadian population (Gottlieb & Peters, 1991).

Health Promotion Policy supports self-help/mutual aid in Canada

Marc LaLonde, minister of Health and Welfare Canada—then the top government official in health and welfare—argued in a 1974 report that the health care system was too disease- and treatment-oriented and that a broader view focusing on good health should be taken (LaLonde, 1974). His widely influential report was adopted in Canada and subsequently in Europe and by the World Health Organization. In 1986, Jack Epps, a Canadian health minister, extended LaLonde’s ideas into a general framework for health promotion in Achieving Health for All (Epps, 1986). Mutual aid/self-help was explicitly mentioned as one of three strategies of health promotion along with individual and community interventions. LaLonde’s and Epps’s frameworks of health promotion became public policy in Canada (Pinder, 1994). A social movement in health promotion that used the same discourse engaged federal government leaders, activists, health care providers, community leaders, and academics in Canada and Europe but not in the United States (Pederson, O’Neill, & Rootman, 1994).

Subsequently, province-level health promotion agencies adopted the LaLonde–Epps framework and adapted it to fit their circumstances. In 1986, Ontario province established a health promotion branch similar to the national-level Health Promotion Directorate. A community-wide strategy of planning and implementation of health promotion policies and interventions was adopted (Ontario Ministry of Health, 1991); throughout the planning document, self-help/mutual aid—including SHGs and related mutual support networks—is explicitly described as fitting within the framework. This health promotion policy, which explicitly lists SHGs and related networks, was an extremely important conceptual framework: SHGs and other mutual aid initiatives were legitimized and made an integral part of health policy.

The Provincial health promotion branch had working committees composed of community groups, health care providers, and health care organizations to advise the government on its health promotion initiatives. The Metro Toronto Self-Help Resource Centre was a member of a major working committee representing the interests of SHGs, promoting the self-help/mutual aid agenda, and educating community leaders and health care about the value and nature of self-help/mutual aid. Although the Centre did not qualify as a line item in the Provincial health budget, it received special grants for operating funds over several years. Further, the Centre’s proposals for special projects such as the Ontario Self-Help Network project were funded. The Centre also received funding for special projects such as the Family Councils Program from the private, quasi-governmental philanthropic organization named the Ontario Trillium Foundation that received its money from lottery proceeds. The Family Councils Program facilitated mutual aid among family caregivers of relatives living in nursing homes.

Canadians, as did Europeans, assumed that the government could fund private nonprofit agencies without necessarily co-opting or otherwise compromising the agencies’ integrity (see Krashinsky, 1990; Wolf, 1985); this reflects in part their value of pro-government—a higher level of trust in government to solve social and health problems (see Lipset, 1989).

Health Promotion in the United States Neglects Self-Help/Mutual Aid

Health promotion in the United States was not a significant part of government health policy but more of a professional movement found in university schools of public health and medicine. Disease prevention was often discussed separately from health promotion, where specialized silos such as for heart disease focused on prevention from heart disease, for example. Health promotion discourse was not linked with the European and Canadian movements. Some critics (Green, 1994) argued that, despite the rhetoric, health promotion in the United States was often linked to and equated with “health education,” which tended to be individual interventions instead of the multifaceted Canadian approach. Very importantly, health promotion discourse does not explicitly include self-help/mutual aid. Accordingly, friends and supporters have to develop elaborate arguments and justifications of how self-help/mutual aid fits with disease prevention or health promotion.

In Kansas, no state-level office of health promotion exists, and state-level government support is for specialized projects. The mental illness area appears to be the most likely to receive specialized government support for self-help/mutual aid projects. For example, the Self-Help Network collaborated with a mental health consumer/survivor organization to obtain funds from the State Department of Mental Illness and Retardation, with the Network contracting to do the evaluation research facets of the grant.

Two private philanthropic organizations—health foundations—funded major initiatives of the Network, such as the publication of the statewide directory of SHGs. Two health foundations had been formed in the 1980s from the sale of a large nonprofit hospital to a for-profit hospital corporation. One foundation funded projects in five areas: primary care education, public health, health policy and research, health promotion and disease prevention, and rural health. They funded a special Network project in training self-help leaders as resources throughout the state, which was regarded as overlapping with the priority of rural health since so many self-helpers were in rural areas of Kansas. The second foundation was a Protestant-related health foundation that funded treatment services for low-income people without health insurance. The Network’s emphasis on lay people leading self-help groups appealed to the religious orientation of the foundation (Borkman, 1996a, p. 26).

Thus, in Kansas, funding of the Network’s projects were more from private philanthropies, with government funding for specialized projects in a few areas. Kansas did not have a policy of health promotion and disease prevention as integral to their health policies as did the Province of Ontario in Canada.

***2.2.3 Federal Government Support of Self-Help/Mutual Aid in the United States***

In the United States there was no national-level health policy. A number of federal agencies selectively supported SHGs and SHOs within their silos during the 1970s and 1980s. For example, the Maternal and Child Health Bureau supported conferences and projects for people with genetic diseases, culminating in an Alliance of Genetic Support Groups (1986). The Bureau also supported the development of a nationwide network of chapters of Parents Anonymous (see Lieber, 1984) for preventive measures for parents who abuse their children. Probably the most consistent and intensive support came from the Community Support Program of the National Institute of Mental Health to fund a variety of initiatives for ex-mental patients and persons with severe and persistent mental health problems, as described in Section 2.1.5.

The federal government’s most significant major initiative to support self-help/mutual aid was in 1986–1987, when then-Surgeon General C. Everett Koop convened a planning committee of leaders of SHGs, SHOs, and self-help centers along with academics, health care providers, and policy makers to implement an invitational Workshop on Self-Help and Public Health in 1987. Surgeon General Koop was very familiar with the value of patients talking to each other: “As a pediatric surgeon in the 1940s, I observed that one of the most important ways I could help struggling families was by introducing them to one another. The benefits of mutual peer support were also experienced by our medical staff as we came together to deal with our own grief and stress in reference to dying children” (Koop, 1992, p. xvii).

The surgeon general’s position is partly ceremonial, as no budget is associated with it to initiate projects. Twenty-seven people on the planning committee represented self-help clearinghouses; government health agencies; health professional organizations such as the American Medical Association; SHOs such as the National Alliance on Mental Illness (NAMI), International Polio Network, and National Black Women’s Health Project; health philanthropies; and social science researchers. Surgeon General Koop charged the attendees with developing recommendations for “how self-help and public health can work more closely together toward the common goal of personal well-being” (Koop, 1987, p. 7). Twenty-three states and the District of Columbia were represented by the 175 invited participants, who were equally divided by gender and by the role of human service providers and self-helpers, with 27 percent of the participants being of racial minorities (Dory, 1988, p. 13). The two-day conference of small workshops, general sessions, and decision-making sessions yielded sixteen recommendations, to which Surgeon General Koop responded to the extent that he could.

The Surgeon General was able to persuade the Maternal and Child Health Bureau, which had funded a number of self-help projects, to fund a National Council on Self-Help and Public Health for three years that would represent self-help/mutual aid on a national level and advise the Surgeon General in implementing the recommendations of the Workshop (Hedrick et al., 1992). A detailed description of the activities of the Council is found in Hedrick et al. (1992); they include advising federal agencies on incorporating self-help/mutual aid initiatives into their projects, stimulating publications in professional journals, encouraging more training in self-help/mutual aid for pre-professionals and professional health care providers, and, especially, stimulating awareness that minority and lower-income populations need additional assistance in developing culturally appropriate self-help/mutual aid initiatives. The Council also developed a database of 200 researchers interested in self-help/mutual aid; the database was given to the Self-Help and Mutual Support Interest Group of the Society for Community Research and Action (SCRA)—the professional association for community psychologists—at the conclusion of the project.

Other national-level projects were initiated as a result of the Surgeon General’s Workshop on Self-Help and Public Health. The 1989 Symposium on the Impact of Life-Threatening Conditions was a significant one, with the theme of developing partnerships between SHGs, SHOs, and other initiatives on one side and health care providers and their agencies on the other. The keynote speaker, Fitzhugh Mullan (the director of the Bureau of Health Professions), called for rewriting the social contract in health, in which “veterans helping rookies” from SHGs—and not just interactions with health professionals—would be an integral aspect of patients receiving care. In 1992, a book titled *Self-help: concepts and applications* (Katz et al., 1992), with a foreword by former Surgeon General Koop, chronicled many of the presentations of the Symposium. Aside from specific publications and notices of activities, little to no evaluative materials are available with which to assess the longer-term results of the above actions; T. J. Powell (1994) thought that the Surgeon General’s Workshop on Self-Help and Public Health had yielded little in long-term benefits, but he offers no evidence one way or the other.

In 1990, the federal Office of Disease Prevention and Health Promotion (ODPHP) was small with few staff (e.g., the 1991–1992 budget for prevention activities was $4.6 million, half that of the National Vaccine Program, which had $9.6 million). An important supporter of self-help/mutual aid within the federal government at the time was Fitzhugh Mullan, MD. Mullan was a cancer survivor who understood the value of SHGs, as he had personally participated in them. He promoted the idea of self-helpers as experientially knowledgeable persons who needed to be better integrated into the health care system (Mullan, 1992). However, his energy was soon diverted to developing a national coalition of advocacy and support for cancer-related organizations, thus neglecting self-help/mutual aid in general. This story—of an avid and effective supporter who focuses their efforts on one specific disease rather than viewing it as a general strategy of prevention and health promotion across diseases—characterizes a lot of the experience of self-help/mutual aid (Borkman, 1990c). Perhaps a major reason analysts waffle about labeling general self-help/mutual aid a full social movement is because most self-helpers, health providers, and advocates focus on one disease; therefore, national coalitions of SHGs speaking with one voice have not been established. In 2020, the ODPHP is primarily educational and focused on professionals, and it maintains the *Healthy people* series.

###  A last-gasp attempt at influencing federal policy by advocates for SHGs and SHOs was a conference in 1991 involving many professional health care associations and providers, government agencies, and health care advocates. Together, they established the objectives described in the aspirational Healthy People 2000 (Public Health Service, 1991) and Healthy Communities 2000 guidelines for preventing and decreasing disease and disability and promoting health. The conference process by which the objectives were developed favored large, well-resourced, and powerful players, and few of the ideas of the small voices of self-help/mutual aid were heard or accepted. Supporters of self-help/mutual aid ended up being pleased that they had three objectives listed in Healthy People 2000 (Public Health Service, 1991): (1) to increase the number and percentage of people with chronic and disabling conditions who receive information about community resources, including self-help groups (emphasis added); (2) to increase the number and percentage of people who seek help coping with personal problems; and (3) “to establish mutual help clearinghouses in at least 25 states (base was nine states)” (Hedrick et al., 1992, p. 44). According to the Healthy People 2000 Final Review, the second and third objectives above were met, although the table providing evidence to that effect displayed largely blank cells (National Center for Health Statistics, 2001, pp. 132–136). Were there any objectives in the subsequent Healthy People 2010 Final Review pertaining to SHGs or self-help clearinghouses? I could not find any (National Center for Health Statistics, 2012).

## 2.3 A 20th-Century Institutionalization Story: SHGs, Once Radical, Become Part of the Landscape

Researchers writing in the 1970s often saw SHGs as radical for challenging medical authority, but they were vague and unspecific about what those challenges exactly were.[[8]](#footnote-8) We did recognize some radical aspects—the challenge to professional authority and knowledge by using “lived experience.” Further, the egalitarian informal groups signaled a radically different site of help and services than the bureaucratically organized hierarchies of doctor–patient. Even Archibald, who first discussed the institutionalization of SHGs in his book *The evolution of self-help: How a health movement became an institution* (2007), is not specific about how this had come to pass by the year 2000. Now, however, by 2020, the story is clear and its ending can be told in some detail.

By 2000, researchers mostly had lost interest in self-help/mutual aid and turned to the study of peer support, often within the contexts of professionally controlled organizations, mental health consumer/survivor-run initiatives, or addiction recovery.[[9]](#footnote-9) Peer support and consumer/survivor-run initiatives were similar enough to older self-help/mutual aid such that, at first glance, one could be unconcerned about how significant the differences were. Only recently have researchers attended to the large differences that manifest in much peer support and in consumer/survivor-run initiatives when compared to early SHGs and SHOs (Borkman, 2019; L. D. Brown & Wituk, 2010). Peer support in the form of nonprofessional helpers or peer support specialists (who are also known by other titles), who provide services and are supervised or in programs administered by professionals, is not mutual aid. Following Humphreys and Rappaport (1994, p. 219), peer support, as defined above, is not regarded as self-help/mutual aid in this review because the peer (1) has a different, more hierarchical role relationship to their peer in such professionally administered programs; and (2) the source of ideas and organization of services is under professional control, not under the control of the SHG members who share “a common problem in living” and who describe themselves as “members,” not as “patients” or “clients.” Peer support of this type is regarded in this review as an *offshoot* of self-help/mutual aid—that is, peer support has some features of self-help/mutual aid, such as interaction with a peer, but lacks the key ingredient of mutual help.

The following story is told from the viewpoint of the SHG research buttressed by research from medical sociology,[[10]](#footnote-10) which explains the medical profession and health care system. Single-issue SHGs were originally radical in challenging medical authority and other aspects of the health and welfare systems by their sheer existence, if not explicitly with social advocacy goals. The story is how SHGs, and self-help/mutual aid more generally, prevailed by the time of their institutionalization at the end of the 20th century.

The 1950s and 1960s were known as the “golden age” of physician dominance and sovereignty (Friedson, 1970; Light, 2000). Physicians belonged to a profession defined as a specialized occupation that was granted by the state the exclusive right of domain over the diagnosis, treatment, and care of disease and illness (Friedson, 1970; Light, 2000), and the profession was allowed to monitor and sanction their own members’ behavior. Physicians had a monopoly on the right to name diseases and diagnose and prescribe treatments for patients. In exchange for these rights and privileges, physicians were expected to eschew material wealth in exchange for an ethical approach to treat all patients equally and without favoritism (Friedson, 1970; Light, 2000; Starr, 1982).

Physicians were paternalistic toward patients, and they expected deference and compliance with their prescriptions and medical orders. Patients were studied in limited ways by the newly developing specialty of medical sociology (Rier, 2010). Patients did not have the right to solicit second opinions, were usually not given options but were expected to accept the MD’s decisions about treatment (or reject them and walk away), and, of course, did not participate in any way in any policy making, research, or health care committees or advisory boards.

Public health and medical science had made great strides in conquering infectious and communicable diseases by the 1950s and 1960s, and sickness, ill health, and deaths were increasingly from chronic conditions. Information was accumulating about risk factors such as smoking, excessive alcohol, obesity, proper nutrition, adequate exercise, and so forth. Chronic disease prevention and management required much more active participation and self-care from the patient than the era of infectious diseases. Lowell Levin (1990), writing about chronic diseases, estimated that 70–80 percent of care necessary to prevent or manage chronic disease was dependent on the patient, and much of it at home in the form of self-care. Self-care was needed on a continuous basis for a long period of time, contrary to the short-term intensive period of help needed from health care professionals where infectious diseases were concerned. The health care system was slow to adapt to changes required by chronic diseases (see Cockerham, 2002). Society was then quite stigmatizing of people who had different physical and social challenges, just as it stigmatized asking for help (Goffman, 1963; Schein, 2011).

Chronic diseases, by their continuing nature and requirements for intensive self-care, create a large difference in the interests of patient and physician. For the physician, chronic diseases are complex, multifaceted, and may be more difficult to treat than many infectious diseases; further, the patient has to engage in many practices to manage their chronic disease in their natural home setting, of which the physician has less knowledge and control over compared to the clinic or hospital setting. Medical sociologists captured these differences by distinguishing between physicians’ focus on *disease*—that is, the physiological, clinical entity and its related technical aspects—and patients’ concern with their *illnesses* and the impacts on their entire lives (Haug & Lavin, 1983, p. 38). This distinction highlights the increased possibility of divergence between their two perspectives and the increased potential for conflict and dissatisfaction. SHGs and SHOs began innovating new “ways of living” with chronic diseases before medical sociology distinguished between illness and disease, but the distinction is a key to appreciating the different perspectives of the physician and health care system on one hand, and SHGs and their communities, including families, on the other.

A typical way that physicians and the health care system handled chronic disease then was to encourage the patient to continue their regular life as much as possible, but adjust to the special needs (e.g., for diet, medication, exercise, or health care visits). In effect, regular life is put in the foreground, and the chronic condition is put in the background. Meanwhile, SHGs and SHOs were innovating and creating new and satisfying ways to deal with these chronic diseases.

One example of how different and radical SHGs were, albeit quietly and without a lot of strident advocacy, can be found in Robinson and Henry’s (1977) research in England. As Robinson and Henry articulated, SHGs for chronic diseases reversed the typical professional equation: Mutual help puts the chronic condition in the foreground and regular life in the background. But in the process they change the meaning of asking for and receiving help; “patients” redefine themselves in relation to their chronic condition, and develop a new “way of life.” The chronic condition is reinterpreted as a challenge rather than as a sickness. They develop a continuously available network of support in which help giving and receiving are commonplace. Paradoxically, the chronic problem in their new “way of life” is no longer a “problem,” but the means to a satisfactory way of living with their situation. From the individual’s point of view, participating in an SHG helps them to develop a new “way of life,” which includes new meanings that provide higher self-esteem, a modified identity, and a network of friends, experiential peers, and other sources of help. The SHG is also a means to the end of developing a community that supports the new “way of living.” SHGs then become organizational vehicles for building community. Groups interviewed by Robinson and Henry believed that if a strong community were developed, the group per se could wither away, as it would not be needed; until that happens, the SHG and its meetings are important sites for experiential peers to connect, to have sharing circles in which they develop collective experiential knowledge, and to have a network of supportive social relationships.

Another example of creativity and challenges to existing human services are the self-help organizations (SHOs) found in a midsize city in the northeastern United States, studied by Steinman and Traunstein (1976). The more formalized SHO was defined in terms of five criteria: a minimum of 10 members; a majority of members, including officers and board, establish and run the organization in order to provide themselves with services that are unavailable or unacceptable elsewhere, and a majority of members or their children benefit directly from the services provided; half or more of the membership share a condition defined by the larger society as problematic or stigmatizing; half or more of the governing board is composed of those who share the stigmatizing condition; and, at least initially, the contribution of professionals at all levels is not central. In a city with about 100 professionally based bureaucratic human service organizations, they found forty-eight who fit their criteria of a SHO and interviewed them. Over half of the SHOs stated that their most important goal was to change either (or both) the public’s and their members’ image of their condition from “deviant” to “different”—that is, to destigmatize it. Their findings included the following: SHOs rejected the professional’s claim of exclusive domain over treatment; acted with considerable autonomy in the effort to influence how the members defined the condition; involved consumers/members in governing the SHO while providing them with services; established a self-help service network as a partial alternative to professional bureaucratic services; gave greater authority to personal involvement than to expert professional knowledge as a basis for understanding and solving the problematic issue; replaced (or supplemented) professional therapeutic interventions with peer counseling; and promoted social and emotional involvement among members as a substitute for the conventional affective neutrality and objectivity of professionals and bureaucracies (Steinman & Traunstein, 1976, pp. 359–360).

What became known as the consumerist movement in medicine (Haug & Lavin, 1983; Timmermans & Oh, 2010) and the health social movements (P. Brown & Zavestoski, 2005a; Light, 2010) challenged medical dominance by advocating for greater patient participation in matters affecting their bodies. The consumerist movement had relatively minor demands (in comparison with those of SHGs and SHOs), such as greater access to information about their health conditions, if not access to their medical records; and they challenged the physician’s right to make unilateral decisions about their treatments. Challenges made by the health social movements and by the self-help/mutual aid movements were more foundational and significant. As described in the preceding vignettes of SHGs (by Robinson & Henry, 1977) and SHOs (by Steinman & Traunstein, 1976) and in our paper (see Borkman & Munn-Giddings, 2008a), they were questioning disease causation, confronting inadequate treatment options, criticizing strategies of prevention, advocating lay participation in policy making, and creating non-stigmatizing and constructive identities.

The civil rights movement precipitated other social movements of marginalized and stigmatized persons, who also claimed the right to redefine themselves in their own terms and give greater credence to their own personal experience and how they had been “treated” by society, instead of capitulating to governing elites’ directives or to professional expert knowledge about them. The growing anti-authority sentiments, beginning with the distrust of governments from the anti-Vietnam War protests, spread to other institutions, including physicians. New paraprofessionals, such as physician assistants and nurse practitioners, as well as the “new careers” movement (Gartner & Riessman, 1977; Haug & Lavin, 1983), contributed by demonstrating that some of the medical role could be performed by less trained personnel. Complementary and alternative medicine (CAM), such as acupuncture and herbalism, also developed during this era; CAM, in and of itself, signaled a distrust of mainstream physicians. SHGs and SHOs were viewed as part of CAM by some analysts, and as part of the consumerist movement and the health social movement (Timmermans & Oh, 2010, p. S97).

The field of medical sociology took the viewpoint of the health care system by ignoring the patient’s perspective until declines in physician sovereignty and dominance led to a changed buyer-driven professionalism. Rier (2010), writing about patient’s experience of illness, noted that studies of patient’s experiences were absent until the later 1980s and early 1990s. Extensive economic changes; the entry of government involvement into health care through at least three separate health insurance plans for different populations (military veterans, Medicaid for low-income people and people with disabilities, and Medicare for persons aged sixty-five and over); the organizational development of corporate managed care; and the “revolt of buyers” (Light, 2010) against the professional dominance and autonomy of the medical profession slowly evolved into a new configuration of buyer-driven “countervailing powers,” including government, health insurance companies, pharmaceuticals, and hospital associations (Light, 2010, p. 278). Light succinctly summarizes the evolution as being from professional dominance to countervailing powers (2010); he further describes the changed professionalism of physicians as the “accountability-based new professionalism” (2010, p. 279). The new professionalism represents a shift from a training-and-licensing model to a competency/performance model of work, and thus to team-based models of care (Light, 2000, pp. 278–279; Britain’s National Health Service exemplifies this model too—see Kuhlmann, 2006). Instead of the MD as sovereign working in a cottage industry who delegates work to nurses and other health care providers, the MD is part of a corporate industry team whose quality outcomes are monitored through guidelines, evidence-based standards, and protocols (Light, 2000, p. 279).

The vast social changes of the last fifty years, from the conditions of the 1950s and 1960s to the 2000s and 2010s, were certainly more than changes to the medical profession and health care systems. Worldwide globalization and the development and resulting pervasiveness of the internet and the digital information society, all of which constitutes as fundamental a shift as going from an agricultural to an industrial society, occurred along with economic, social, and cultural shifts. Archibald (2007) states that why and how self-help/mutual aid changed so extensively from the mid-20th century to the century’s end, and how it became institutionalized, have not been studied and are thus not well understood. However, it happened.

I maintain that the self-help/mutual aid movements that have been described in this capstone review from the 1950s to the present were overall successful in achieving their most significant goals. They did not accomplish the changes solely by themselves, but rather had a vast array of other social movements and societal trends that moved the changes in the same direction and reinforced the changes they helped create. Further, not all their goals have been met.

The changes will be shown in two ways. First, a case illustration of Clara, who had very different experiences with physicians and the health care system with two instances of breast cancer in 1979 and in 1997, will be described. Then the major accomplishments of the SHGs will be listed.

\* \* \*

Case Illustration 6

Clara’s Experience of Breast Cancer without Support (1979) and with Social Support (1997)

Clara, a White, middle-class, divorced mother of four children in her thirties, who identified as a feminist lesbian, lived in the San Francisco Bay Area and was progressive in following her doctor’s advice to get a mammogram every year. Her routine mammogram in 1979 revealed a suspicious lump in her breast. Upon awakening from the biopsy in the recovery room, Clara reported, “this giant person loomed over me in his green outfit and he said, ‘Well, it’s cancer! Do you want me to cut it out now or in a couple of days?’” (Klawiter, 2005, p. 169).

At the time, physicians were allowed the “one-step procedure” in which patients signed a form in advance, authorizing the surgeon to perform an immediate mastectomy if cancer were found or believed to be found. Later that year in 1979, the National Institutes of Health convened a Consensus Development Conference on primary breast cancer and issued a series of findings, including a nonbinding recommendation that surgeons abandon the “one-step procedure,” separate the diagnostic tests from treatment, and discuss treatment options with patients.

After making arrangements for the care of her children, Clara returned to the hospital for a radical mastectomy. When she met her medical oncologist, he determined that no additional treatment was necessary, but recommended elective reconstructive surgery because he had seen “many marriages flounder on the shoals of a mastectomy” (Klawiter, 2005, p. 170). As Klawiter described it, Clara “thought how do I explain I’m gay and our relationships are different. She got confused about what to say, said nothing and declined the reconstructive surgery” (Klawiter, 2005, p. 170).

From the health care system’s point of view, Clara’s rehabilitation was simple and fast. The only institutionalized form of support for breast cancer patients was Reach to Recovery, a program adopted by the American Cancer Society in 1969 to provide support and practical advice to breast cancer patients after surgery. I had studied Reach to Recovery when it was created by a breast cancer patient to help herself and peers after surgery. In order to have her program accepted, she had to relinquish control of it to physicians, who redesigned it with many restrictions, a script for volunteer patients to follow, and training to follow the script and other limitations. In this early period, medical personnel were wary of patient volunteers in self-help groups giving erroneous advice about medical matters to their patients, and they knew of few or no benefits of patients talking to each other. The goal of the program was for the woman to re-enter her former life and become the woman she had been before surgery—in physical attractiveness. There was no concern about developing a supportive community or social network (Klawiter, 2005, p. 172). The breast cancer regime that Clara faced in 1979 emerged after World War II, but was changing by the early 1980s. At the time, physicians had sovereign power over their sphere of practice, and patients were expected to comply with the limited options they were given. Patient participation in decision making in health was at best rudimentary, and very little social support was available.

Almost two decades later in 1997, Clara was diagnosed with metastasized breast cancer, but she faced a significantly changed health care system: one with extensive community supports and resources and a more informed and empathic public who had learned from the breast cancer social movement of the past decades. Many support groups at various cancer treatment centers and SHGs in the community were available as were online groups, workshops, and other forms of support: “Women with breast cancer had become a visible presence in the public domain and breast cancer survivors were now heralded as heroes rather than pitied as victims” (Klawiter, 2005, p. 181). Many more options were available from complementary and alternative medicine and within mainstream medicine. Clara attended a workshop while contemplating undergoing a stem cell transplant, and developed a network of similarly situated patients as friends from the experience. In 1979, she felt isolated, powerless, and unable to disclose her lesbian status; in 1997, she felt understood, and like the “captain of a well functioning team dedicated to aiding and assisting her treatment and recovery” (Klawiter, 2005, p. 176).

Sociologist Maren Klawiter, author of the paper “Breast cancer in two regimes: The impact of social movements” (2005), had interviewed Clara in 1998 while studying four activist organizations for the breast cancer social movement in the San Francisco Bay Area over a four-year period. Klawiter maintains that her study contributes the concept of a *disease regime*, which allows us to study structures as practices and enhances our ability to contextualize the shaping of illness experience (2005, p. 181). She proposes that the study shows how social movements change the illness experience in two ways: “by changing the sufferer’s relationship to the regime of practices, and by changing the actual practices of the disease regime” (2005, p. 182).

\* \* \*

## 2.3.1 Self-Help/Mutual Aid’s Accomplishments

Clara’s story exemplifies some of the accomplishments of the self-help/mutual help movements. Following is a more comprehensive list of those achievements made because of the overall self-help/mutual aid group movement. Following that, achievements specific to each mutual aid movement are listed by the movement: addictions recovery, the general self-help group movement, and the mental health consumer/survivor group movement.

Some major changes since the 1950s and 1960s that have been made in part because of the overall self-help/mutual aid group movement seem to be the following:

* Patient participation and involvement in their health and welfare
	+ Patients receive adequate information about treatment options and their risks, and are expected to choose their treatment.
	+ Patients have access to their medical records and are allowed privacy of those records.
	+ Patients participate on policy boards and in research (with participatory action research).
* Respect for “lived experience” or experiential knowledge of peers as a source of information
	+ Respect for the “lived experience” of patients as important information and support is widely held by health care professionals.
	+ Appreciation that the “lived experience” of patients is a significantly different type of information and support than that from family and friends is widely held by health care professionals.
	+ Research conducted by or with peers on the “lived experience” of health conditions is increasingly recognized as an insider’s viewpoint.
	+ Support groups and/or SHGs for many health conditions and for carers and family members are widely used and routinely available in hospitals, clinics, and other health care and living facilities.
	+ Patients with “lived experience” of a health condition represent patients on health planning, research, and advisory boards.
* Recognition of and implementation of social supports as necessary to health and well-being
	+ SHGs and support groups are accepted by society as a form of social support.
	+ Many lay people know how to develop a new SHG (Borkman, 1990c).
	+ SHGs and support groups are accepted as alternatives to professionally based psychotherapy or counseling.
	+ New forms of peer support are created and taken for granted, such as buddy or sponsor systems, warm lines and hotlines, alternative forms of peer communities and families.
	+ Health care systems are on the verge of regarding the lack of social support as a risk factor for morbidity and mortality.
* Destigmatized statuses and conditions with constructive non-stigmatized identities
	+ Many formerly “deviant” statuses and conditions have been redefined and renamed in destigmatized forms.
	+ Voice: People with a previously stigmatized status or condition have taken or been given the right to speak on behalf of their status or condition (i.e., African Americans, not the political elites, speak for African Americans).
	+ People with previously stigmatized statuses or conditions have taken or been given the right to name themselves (e.g., a national coalition of mental health consumer/survivors in the United States chose to name themselves “mental health consumers/survivors”; Fisher & Spiro, 2010).
* Many peer-created, peer-led, or peer-inspired alternative community-based interventions, “treatments,” and recovery supports are being developed (e.g., mental health courts and drug courts as alternatives to jail in the criminal justice system).

In addition, each of the three self-help/ mutual aid group movements described in Subsection 2.1 added specific achievements, some of which are briefly listed here:

1. Addictions recovery movement
	* The Recovery movement became a general cultural phenomena (Room, 1992).
	* AA helps more people in a year than all professionally based treatment programs put together in the United States.
	* The 12-step/12-tradition addiction groups constitute role models by their sheer existence.
	* AA has become a worldwide phenomenon and is found in 150 countries.
	* AA has inspired many other addiction groups and other SHGs.
	* AA’s small-group form of organization demonstrates an alternative to the idea that informal organizations automatically develop into bureaucracies.
	* AA inspires the creation of many spinoffs and offshoots, such as the California social model of substance abuse recovery, the Minnesota Model of substance abuse treatment, and Oxford Houses—democratic, peer-run residences for recovering substance abusers.
2. General self-help/mutual aid group movement
	* The women’s health movement, with its CR (consciousness-raising) groups, developed more control over their bodies, especially in relation to the health care system; they invented collectives, changed gynecological practices, and so forth (Morgen, 2002).
	* The HIV/AIDS movement in the 1980s developed social supports such as buddy services as well as hybrid supportive and advocacy services (Chambré, 2006); AIDS activists directly challenged scientific knowledge research production, and were successful both in getting clinical trials modified in terms of rules, timing, conduct and in being represented on scientific decision-making advisory boards (Epstein, 1996).
	* Breast cancer feminist activists challenged the treatment protocols of surgeons and, along with evidence from clinical trials, succeeded in getting treatment protocols changed and increasing their involvement in decision making (Lerner, 2001).
	* People who stutter confront inadequate treatment options, criticize strategies of prevention, and fashion new, constructive, non-stigmatized identities (Borkman & Munn-Giddings, 2008a, p. 143).
	* People with hundreds of kinds of health conditions find support, know they are not alone, and gain strength from their SHG participation.
	* Mothers’ postpartum depression is recognized as a serious problem and is less likely to be criminalized, but rather successfully treated within the health care system (Taylor, 1996).
3. Mental health consumer/survivor group movement
	* Some people with serious mental health problems, such as personality disorder, who questioned medical definitions of disease causation, have seen more satisfactory conceptualizations that allowed them to receive treatment (Castillo, Allen, & Coxhead, 2001).
	* Advocates have succeeded in getting government funding of consumer/survivor- organizations in the United States and in getting representation on many government advisory committees in the United Kingdom.
	* In the United States there are more units of mental health self-help groups, consumer/survivor-run initiatives than professionally based mental health units in hospitals or specialty clinics (Goldstrom et al., 2006).
	* People with some kinds of serious and persistent mental health problems have developed alternative enclave communities (Mandiberg, 2010) or new “ways of living” in the community with accompanying destigmatized identities (Rappaport, 1993).
	* Recovery from severe and persistent mental health problems to lead a constructive and meaningful life in the community is now possible and is being developed.
	* Gradual attempts to transform the professionally based mental health paradigm into a community- and recovery-based paradigm are under way (Myrick & del Vecchio, 2016; Nelson, Kloos, & Ornelas, 2014).
	* Constructive, alternative non-stigmatized identities other than “mental patient” are available for members of some SHGs, such as GROW or Recovery International.

While many accomplishments can be and have been chronicled, other challenges remain. In general, the collectivized experiential knowledge of developed groups has neither been recognized nor appreciated in most countries, with Germany being an exception (Borkman & Munn-Giddings, 2020; Munn-Giddings, Oka, et al., 2016; and Section 4 of this article). Some illnesses and diseases, especially rare genetic ones or contested disorders (see Hearn, 2006, for discussion of online advocacy groups for fibromyalgia and other functional conditions in Germany and in the United States), remain resistant to medical acknowledgment or understanding. The US federal government even provides a list of support groups “for individuals with an undiagnosed condition and their families” on the National Institutes of Health website dealing with rare or genetic diseases (Genetic and Rare Diseases Information Center, n.d.). With institutionalization has come misuse and abuse or exploitation of older concepts of self-help/mutual aid, with the result that some present-day instantiations of it are so different as to be unrecognizable as mutual aid, but that is another story—the story post-institutionalization.

# 3 Research From the North American Perspective in the 1990s and after

As self-help/mutual aid became institutionalized in the 1990s and globalization intensified, North American research expanded, broadening to learn about parallel self-help/mutual aid efforts internationally. It matured methodologically by developing collaborative relationships and long-term studies of some SHGs, and accumulated a modest body of findings on such issues as internal dynamics within groups and the benefits and outcomes of participation. Each of the three strands—addictions recovery, the general self-help/mutual aid group movement, and mental health consumer/survivor movement—developed in their own related but distinctive ways. AA’s retaining of its distinctive small-group structure became a prominent if unrecognized (and unacknowledged) influence on addictions treatment in the United States, both within mainstream, professionally dominated treatment and in the self-help/mutual aid world. In the general self-help/mutual aid group movement, the diversity of organizational forms, group practices, and relationships with professionals, among other features, was striking. The mental health consumer/survivor movement continued to grow, especially by enlisting government funding to develop registered nonprofit organizations that provided drop-in or wellness and recovery services. These were legally limited entities prohibited from conducting explicit advocacy activities, and they developed alongside mainstream services but were subservient to them.

This section, which describes these developments, is divided into four subsections, beginning with a brief look at how the North American researchers expanded their horizons by looking internationally. This is followed by a discussion of the conceptual frameworks by which SHGs and SHOs were viewed—whether as human services, voluntary groups and organizations in civil society, or supportive social communities—along with the methodological strategies they employed. Third, the subsection “Inside the Rooms” pertains to who participates in groups and what their demographics are. It addresses how the internal dynamics of SHGs are theoretically and empirically linked to benefits and outcomes; for example, one framework’s dynamic mechanisms of change are another’s benefits or outcomes of participation. Because of this, the mechanisms of change and benefits and outcomes are considered together rather than separately. Fourth, and finally, spinoffs and offshoots of 20th-century SHGs are very briefly listed in a subsection titled “Outside the Rooms.”

## 3.1 International Research on Self-Help/Mutual Aid

SHGs and mutual aid initiatives sprang up in many European and other industrialized countries in the 1950s and later (Barath, 1991), but the North American research traditions, with few exceptions, focused on the United States and Canada (for the exceptions, see Katz & Bender, 1976b; Pancoast, Parker, & Froland, 1983). Overcoming this parochial approach, the Canadians hosted the first International Conference on Self-Help/Mutual Aid in Ottawa in 1992. Self-help group leaders and members participated in workshops, and research papers were presented and then peer-reviewed and published as a book that was simultaneously published as a double issue of the journal *Prevention in Human Services* (Lavoie, Borkman, & Gidron, 1994). The great diversity in self-help/mutual aid revealed at the conference was dealt with by Benjamin Gidron of Israel and Mark Chesler of the United States, who presented a framework for international and intranational analysis that included universal and particularistic attributes of self-help/mutual aid (Gidron & Chesler, 1994). First, they offered a universally applicable definition of self-help/mutual aid: “The recruitment and mobilization of peers in an informal and non-hierarchical setting, and the sharing of common experiences, are the basic building blocks for almost all forms of self-help, in all nations and cultures” (p. 3). Then, they outlined the dimensions that accounted for the particularistic differences in the wide variety of self-help/mutual aid internationally: (1) national differences in governments, civil society, and the relationship between the government and citizens; (2) various demographic statuses and racial and ethnic cultures, which define relationships between kith and kin and the place of individuals within communities; and (3) the issues or problems around which groups and organizations are formed (Gidron & Chesler, 1994, p. 3).

In 1994 the Addiction Research Foundation of Ontario hosted an international conference that invited researchers to present on addictions mutual aid from a comparative perspective (Ogborne, 1995). Three conference sessions were devoted to the just-completed international collaborative study of Alcoholics Anonymous, where autonomous researchers from eight countries “sought to collect comparable data using a common frame of reference” (Gidron & Chesler, 1994, p. 201). The major publication (Mäkelä et al., 1996) had nineteen coauthors from the eight countries, which included three Nordic countries (Iceland, Sweden, and Finland), two Western European (Austria and Switzerland), one Eastern European (Poland), the United States, and Mexico. A companion publication titled *Diversity in unity* (Eisenbach-Stangl & Rosenqvist, 1998) contained case studies of each country’s AA groups.

In Europe, the WHO’s European Regional Office hosted meetings of self-help group leaders, members, and researchers in the 1970s and 1980s. Nicki Hastie, who was then the Information Officer of Self Help Nottingham, summarized the major conferences and meetings of practitioners and researchers (Hastie, 1999). In 1978, the WHO promoted “Health for all by the year 2000,” declaring that “people have a right and duty to participate individually and collectively in the planning and implementation of their health care” (Hastie, 2000, n.p.). Worldwide, SHGs were seen as concrete expressions critical of the professional model of health care and speaking for the need of people to gain greater self-determination and involvement in their health and self-care (Katz, 1984). England and Germany especially reported the development of SHGs (Bradburn et al., 1992; Humble & Unell, 1989; Robinson & Henry, 1977). In the late 1980s, England’s three-year Self Help Alliance of eighteen projects in different areas helped form 500 new SHGs and assisted 1,000 already-developed groups in increasing their activities and membership (Cartwright, 1989, p. 208). Self Help Nottingham, a clearinghouse and resource center for Nottingham and its surrounding area, not only assisted in the formation and sustainability of many SHGs, but also supported research (Hastie, 1999). After the year 2000, Self Help Nottingham was renamed Self Help UK and charged with supporting and developing SHGs around the country. British researchers were especially attuned to the importance of SHGs for excluded or marginalized communities. As Burns and Taylor (1998) said about middle class communities, SHGs “may be seen as one strand in a web of choices. For people who are socially excluded and on low incomes they are often the only way of coping where there is no alternative safety net” (p. 29).

From the mid-1990s on, SHG research became more international in perspective as researchers interacted with others at conferences, collaborated on cross-cultural research, and found common publication outlets. Two important events signal the gradual erosion of strong barriers between the research traditions: the development of the *International Journal of Self-Help & Self-Care* in 1999, and an article in 2016 on SHGs as volunteers—published in an international research handbook—written by an international set of authors from Europe, Japan, United States, Mexico, and Africa (see Munn-Giddings, Oka, et al., 2016). The journal, founded by Alfred Katz at the University of California, Los Angeles, was published from 1999 to 2014, and contained articles from around the world about addictions recovery as well as about the psychosocial research traditions. The international handbook article signposts the gradual decrease in research on SHGs and SHOs. Attention had gradually shifted from the late 1990s to research on peer support, spinoffs such as Oxford Houses, offshoots such as Fountain House clubhouses, or mental health consumer/survivor (or service-user) run initiatives.

I was heavily involved in international research from the 1990s onward and developed a loose research network with these international allies. To illustrate some of the insights gained from these international explorations, a case illustration of events in various countries follows.

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Case Illustration 7

Borkman’s International Odyssey of Self-Help/Mutual Aid

I was privileged in my career to have a series of opportunities to travel internationally, beginning in the 1990s. Further, I had international guests whom I mentored in the researching of SHGs; they included Magnus Karlsson from Sweden in 2003, Tomofumi Oka from Japan in 2004–2005, Tehseen Noorani from the United Kingdom in 2010, and others more informally. What I call my “international odyssey” is summarized in Table 5, which details for each event in my journey the date, location, insight gained, the section of the present literature review where the event is discussed, and associated publications for the particular event (if any).

Insert Table 5 about here

The most dramatic differences in self-help/mutual aid were seen in non-Western countries such as Japan, Hong Kong, and Taiwan, or in post-Communist countries such as former East Germany in the early 1990s after reunification with West Germany or in Croatia and Slovakia. Section 4, written by Carol Munn-Giddings and Melanie Boyce, describes research from several European countries that illustrate how self-help/mutual aid is affected by its surrounding societal, health, and welfare systems and civil society contexts.

One interesting project revealed how former East Germans had to learn about SHGs after German reunification—a process described by Ursula von Appen. I met Ursula at the International Conference on Self-Help/Mutual Aid in Canada and visited her in the summer of 1994 in Schwerin, Germany.

Shortly after the reunification, from 1991 to 1993, Von Appen (1994) directed a new pilot project, an Information and Contact Center for self-help groups (the equivalent of a self-help clearinghouse); it was in Schwerin, the capital of Mecklenburg–West Pomerania in northern Germany, a state that borders the Baltic Sea, and which was previously part of Communist East Germany. The government-owned and government-controlled health and welfare system had been all-encompassing, and the few voluntary associations (e.g., under the auspices of the relatively autonomous Church) were tightly regulated. Consequently, the citizenry expected the government to handle their health and welfare needs, and they lacked the opportunity to develop skills or values related to the benefits of engaging in voluntary action. Von Appen described the situation:

Well-researched and established self-help programs are being offered to people in the new eastern provinces who at first knew nothing about the concept and could not imagine what it might entail. It is unthinkable for many suffering under physical or psychological hardship that something might be done in the way of self-help without the assistance of doctors, psychologists or the state health system. (1994, p. 103)

It took several years of working closely with people in new groups, with professionals first teaching members how to set agendas and run their own groups, before the groups could become self-sufficient. Women seemed to be more active than men in developing new groups (p. 105). Von Appen offered two interesting insights about the professionals’ initial reactions to the SHGs: First, some doctors and psychologists asked her about their patient’s activities in SHGs and expected the Contact Center, in effect, to monitor the patient’s involvement with the group, which the Center refused as inappropriate. Second, after an initial period of hostility or skepticism, some professionals became willing to consider collaborating with the Center (Von Appen, 1994, p. 107).

Research from several Asian cultures reports that citizens are reluctant to openly share their feelings and emotional experiences with strangers in support or self-help groups, especially when it involves their family members or criticism of them (Oka, 1994; Wong & Chan, 1994); this becomes a deterrent to participation in such groups. The many other differences in Asia—such as the tendency toward being oriented to the group or to the extended family, as well as its traditions of skepticism toward empirical social scientific research—are important. I encountered these and other differences.

A former graduate student of mine who had become dean of the School of Nursing at her university in Taipei, Taiwan, invited me to be a visiting professor at her school in June 2000. I was asked to educate the nursing faculty and graduate students about SHGs in health care. The faculty told me they knew of no SHGs in their area. I asked to go to the hospital where they had clinical privileges and trained their students. At the hospital I visited various departments and found support groups and SHGs in the cardiovascular department, in the cancer department, and so forth. The faculty and their graduate students were amazed that these groups had been available yet invisible to them. The Dean then took me on a tour of several Taiwanese cities to make public presentations at hospitals (e.g., I presented at a symposium of self-help groups at the National Cheng Kung University Hospital on June 9, 2010), where we had similar experiences of the nursing faculty not knowing about the support groups and SHGs in various hospital departments. I was struck by how invisible support groups and SHGs were to some areas of health care while being utilized in other departments.

Working with Tomofumi Oka, Professor of Social Work at Sophia University in Toyko, was enlightening, as Japanese social science research differs so much from that of Western democracies. The Japanese non-Western culture and civil society are extensively different in ways that noticeably impact the nature of their self-help/mutual aid. Social science is described in Japan as theoretical in nature with little empirical research, and the Japanese citizenry is not well trained or accustomed to being asked to participate in survey research or other field work (Oka, 2013b). While I found many SHG members and leaders in the United States open and receptive to my requests for interviews, observations of meetings, or other research, Oka reports that many Japanese SHG leaders are skeptical of and hesitant to accept a researcher’s request to study them. The Japanese researcher also incurs substantial obligations to the group they study: They are expected to assist the group in resolving organizational issues, to promote the group to the public, to limit or avoid criticizing the group in publications, and establish a long-term relationship with the group (Borkman & Oka, 2005; Oka & Chenhall, 2006).

Japanese civil society has many customs and laws that can constrain the voluntary emergence of groups, or even participation in voluntary groups (Oka, 2013b). Tomofumi invited me to Japan, where I made a public presentation about SHGs in Yokohama. During the question-and-answer session, an audience member asked me about what to do about changing leadership of groups, stating that leaders tended to cling to their role into old age, when their experiential knowledge of coping with the childhood disease that their now-adult child had is long past, and science has developed new treatment methods (see also Oka, 2003). In effect, the leaders have obsolete experiential knowledge of the focal issue that is unhelpful to the membership. Thinking of the US situation, I flippantly answered the person: “Start a new group, and bypass the old leaders whose knowledge is obsolete.” *No, that is unfeasible*, I was told, as Japanese people are not allowed to initiate a new voluntary group for the same issue for which a group already exists. It was unclear whether civil society laws or custom forbade the development of competing groups, but the conundrum was real. I felt embarrassed to have been so flippant when I could have further investigated the circumstances of the situation.

In contrast to the extreme differences found between Western and non-Western cultures, I encountered very subtle, difficult-to-detect differences between the US and Canadian counterparts of the same SHGs; at first glance, they appeared to be the same. For example, I personally participated in women’s meetings of the same 12-step group in Canada and the United States. To my surprise, Canadian women were very explicit and detailed when sharing about their sexual relationships with partners, boyfriends, or dates, unlike the equivalent women’s meetings in the United States, where the absence of sexual relationships as a topic of conversation implied that it was taboo.

A second difference revealed the more collectivistically oriented Canada. In the same kind of 12-step group as in the previous example, the groups kept records of their members, expected members to attend their meetings or account for their absences, and contacted them if they failed to attend. This would be highly unusual in the United States. Groups might have a voluntary telephone list (which might be out of date); individual friends or networks would check up on each other’s absences, but not as an organized group effort.

Because of the surface similarities in culture but the institutional differences between the United States and Canada (discussed in Case Illustration 5), I became wary of failing to grasp the complexity of the Canadian SHGs. Fortunately, I stumbled onto an extremely beneficial routine for combining experiential learning with research and academic theorizing and reflection. For three days each week I interviewed and observed individuals related to the above project. I volunteered one half day a week at the Self-Help Resource Centre of Toronto, where I not only met leaders and members of various SHGs in the area, health care officials, and others, but was also able to interview officials and people related to my project. Two days a week I traveled to York University in a northern suburb of Toronto, where I met with my host and mentor Professor Vic Murray, then-director of the Voluntary Sector Management Program, and other faculty. We discussed my work; they offered suggestions of people to interview and books and other resources to check out. I learned about when I was misinterpreting areas of Canadian culture or behavior because of my US biases, and I was validated when my interpretations agreed with their understanding of Canadian culture. The following is an excerpt from my personal reflection on that learning experience:

What exquisite ironies life brings! I found that what I observed about self-help group members was also true for me. Self-helpers learn experientially through a cycle of participation in everyday life followed by a period of sharing and listening to others’ similar experiences in the self-help group. The sharing and listening serves as a period of reflection. One then re-engages in one’s daily life with an altered perspective. (Borkman, 1995, pp. 5–6)

This interactive cycle of interviewing and collecting data on SHGs, combined with regular periods of discussing my observations and findings and reflecting upon them with discerning and knowledgeable Canadians, was extremely valuable in learning about subtle differences between the United States and Canada in the face of obvious surface similarities.

My international explorations of SHGs in different contexts has greatly added to my appreciation of how self-helpers are intent on bettering themselves—often with fierce determination—within the context of their families and friends, cultural constraints, and health care and other institutions. I end this piece with a smile at the thought of the hours spent working with Carol Munn-Giddings on my several trips to England, particularly her lovely proposition whenever we were stumped: “A cup of tea?”

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## 3.2 Interpretative Frameworks and Methodological Challenges

This subsection deals selectively with two major topics. First, interpretative frameworks that have been applied to the study of SHGs are examined for the questions they ask and the research strategies they use to answer those questions. Second, the innovative methodological approaches used so creatively by SHG researchers are introduced, especially collaborative research, participatory action research, and cross-cultural research in peer support.

SHGs have been studied through three conceptual frameworks: viewing SHGs as alternative human services, as voluntary groups or organizations, or as supportive communities. Each framework corresponds to one or more disciplinary fields’ ways of studying SHGs and is associated with preferred methodological approaches, each of which has expectations about how one studies the phenomena.

I chose the approach used in this subsection—namely, to present some methodological challenges faced by each interpretative framework—because I myself, as a researcher, had initially ignored some issues, such as problems of gaining access to studying SHGs, until I reflected on why I was discounting the concerns. I have never had problems gaining access to studying a SHG. I laughed out loud when I read that international scientific experts had convened a conference to answer one question: Should and can Alcoholics Anonymous be studied? (McCrady & Miller, 1993; in 1992, a three-day conference in Albuquerque, New Mexico, funded by the National Institute on Alcohol Abuse and Alcoholism convened thirty-five medical and addiction researchers to address this question, and the results of their deliberations are presented in the edited volume by McCrady and Miller). As I reflected upon their perspective—the positivistic emphasis on studying cause–effect relationships, ideally with randomized controlled trials as the exemplar—I understood.

As a sociologist who studied groups regarded as deviant by society and that were therefore secretive or even underground, I learned how to access the groups: Find out where they were locally, visit them, and get acquainted personally with a member or leader as an entrée to becoming acquainted with others; be respectful and show interest in their activities without prejudice; explain what my research entailed and provisions for confidentiality; accommodate their practices in how you collect data; and so forth. I have never had trouble accessing any SHG for research purposes. However, I knew that deviant groups by definition did not have official lists available from which to draw representative samples of groups. In contrast to the approach of addiction researchers, my approach was naturalistic (Kennedy, Humphreys, & Borkman, 1994) and qualitative, aimed at understanding what I could in the phenomenon’s natural settings, not trying to contain them or set up some kind of controlled experimental situation.

Several critical and interrelated facts about SHGs affect and limit the methodological approaches that are appropriate: First, participation is voluntary, which means that participants and members are self-selected and attend when and as they want, and are free to attend, drop out, and choose their level of involvement and participation. Usually, entry is open in the sense that people are free to join or attend as they wish, so the membership rolls (if they exist) of a local group are constantly changing. Many SHGs are small groups that are geographically local and may or may not be affiliated with regional- or national-level organizations; they are unlikely to be on any official list that could be verified and used as a sampling frame from which to draw a representative or geographically based sample. Often citizens create new self-help groups that are structurally vulnerable forms outside of any approval or bureaucratic process that would put them on any official listing; there is no regularized way of maintaining a list of SHGs that would serve, for sampling purposes, as a universe. Any randomization process by a researcher would be inappropriate, as it would negate the voluntary nature of participation. Randomized trials of researcher-designed groups found in the research literature (e.g., see discussion in Humphreys & Rappaport, 1994) are not authentic SHGs, and are therefore excluded from discussion here. Further, since the universe of any kind of group is unknown at any time, striving for representative samples is aspirational. There is usually no set period of time for an intervention, such as the beginning and ending of therapy, and individuals’ goals in participating in the group can change over time—beginners who are hurting with an issue that needs resolving are most likely to tackle their own problem, whereas when their issue is resolved, they may continue their participation in the group in order to help newcomers.

Integrating the interpretative frameworks applied to SHGs with their methods led to the insight that distinctive research strategies and methods are associated with each framework. For example, researchers who conceptualize SHGs as *alternative human services* have tended to use experimental or quasi-experimental designs to assess their effectiveness. Researchers who view them as *voluntary membership organizations* from a third-sector perspective have tended to use case studies. Researchers who have conceptualized SHGs as *supportive communities* have tended to use narrative or storytelling methods to capture the nature of participants’ experiences at the individual and collective level, but they also use quantitative survey methods. To some extent, collaborative and participatory action research (PAR) approaches have been used across the board, but they pertain more to strategies of obtaining and maintaining access to research “subjects,” which often involves inviting them to be coparticipants in the research in order to maintain their cooperation and involvement in decades-long research. Collaborative research and PAR present some difficult challenges, which are described in Case Illustration 8.

As forms of *human service*, SHGs are of special interest to psychologists, who originally contrasted them with professionally led psychotherapy groups (see, for example, Antze, 1976; Hurvitz, 1976, Lieberman & Bond, 1978); they are also of interest to community psychologists and social workers (e.g., Katz & Bender, 1976b). As human services, SHGs have been seen as alternative human services (e.g., Killilea, 1976; Steinman & Traunstein, 1976) and, by the 1990s, as “restructured human services,” in which help-seekers were also help-givers, thus upending the conventional structure and dynamics of serving (F. Riessman, 1990).

SHGs as *voluntary groups or organizations* come under the gaze of interdisciplinary students of voluntary action, nonprofit organizations, and philanthropy—an area of the social world described as the “third sector” (W. W. Powell, 2020) or civil society. This vantage point, adopted by sociologists, political scientists, economists, public policy, and public administration, divides society into four institutional sectors: (1) the state or government; (2) economy or market; (3) voluntary action or nonprofit organizations; and (4) family (kith and kin), household, and informal relationships. The third sector of voluntary action and philanthropy is the area where registered nonprofit organizations receive tax exemptions in exchange for an obligation to respond to society’s needs at a given time (W. W. Powell, 2020, p. 4). Formal nonprofit organizations are defined for technical purposes in the negative; for instance, they do not distribute any profits to their stakeholders, they do not coerce any participation, and they are without “clear lines of ownership and accountability” because they have multiple stakeholders (W. W. Powell, 2020, pp. 3–4). SHGs and other grassroots associations, which are defined as local, community-based, and autonomous volunteer-run groups (Smith, 1997a), are a huge part of the third sector, but are relatively neglected by scholars, and thus constitute the invisible dark matter of the sector (Smith, 1997b).[[11]](#footnote-11)

A third vantage point from which SHGs have been conceptualized is as forms of *social support* or *communities*, concepts that cut across fields of scholarship. Social support did not appear to be studied seriously in its own right until the 1980s, when social support was discovered to be important in maintaining health and longevity (Cohen & Syme, 1985; Vaux, 1988). Communities have long been of interest to sociologists, social workers, urban planners, and others, but the concept has almost 100 definitions among sociologists (see Hillery, 1955). There are so many meanings and connotations that it has become a catchall category with little meaning. Here, *community* will be defined as a form of social organization along three dimensions: ecology (space and time), social structure (interpersonal networks and organizations), and cultural symbolism (identity and culture), where each dimension varies along a continuum (Hunter, 2007). Voluntary groups or organizations are one feature of a supportive community.

Early reviews of research found social support to be a foundational benefit of self-help/mutual aid (Killilea, 1976), and it is often mentioned as an important outcome of participation by SHG members (Borkman, 1999a; L. F. Kurtz, 1997). A rarely cited paper (Borkman, 1984) gave evidence from several SHGs of their routinely helping their members deal with family members who were selectively unsupportive about the focal issue. Felton and Berry (1992) point out that many SHG members develop social networks of support, not just individual friends; regrettably, measurements of social support count individuals, and rarely do they include a category for social networks.

SHGs for serious long-term problems, such as some physical disabilities, addictions, or persistent and serious mental illnesses, can and do create alternative communities, which are variously referred to as “ways of living” (Robinson & Henry, 1977), “enclave communities” (Mandiberg, 2010), “recovery cultures” (White, 2009), and “narrative communities” (Humphreys & Rappaport, 1994; Rappaport, 1993). They are constructive, life enhancing, and identity changing. Rappaport (1993) describes how people with serious mental health problems leave behind a full-time “patient” identity for one as member of a “caring and sharing community.” These various ideas of social support and community are combined into a category I call *supportive community*, which links the idea of community with the constructive features of positive social support.

Each field of inquiry asks some of the same questions about SHGs, but also some different ones. When studying SHGs as a form of human service, the central questions researchers have asked involve comparing SHGs to professionals and their treatments and interventions; their overarching question is, “How is SHG participation similar to and different than professional psychotherapy or other treatments?” The third-sector viewpoint is very oriented to organizational analysis, asking: “How informal or formal is the unit? Given institutional pressures to formalize, what factors create change processes from small group to formal nonprofit organization? How does the voluntary nature of participation affect membership recruitment, maintenance, and longevity? or affect the kinds of research designs that are appropriate to use?” The supportive community viewpoint is interested in such questions as “What are the friendships and social networks that evolve around and because of the SHG meetings? Are family members of the self-helpers included in the community? What activities and goals does the SHG have that contribute to the community? What are the spatial boundaries of the community? Are online internet activities part of the community? What social identities are available in the community?”

Approaching SHGs as alternative human services, both North American research traditions were interested in how effective SHGs were in helping their members. The North American addictions recovery researchtradition maintains a strongly positivistic paradigm, while also having an arm in qualitative research methods. Researchers are often medically trained, or epidemiologists or public health specialists, and they publish in peer-reviewed journals in medicine, addictions, or the biological sciences. Historically, the key research question in the addictions recovery tradition has been whether or not AA is effective in helping participants become abstinent and maintain abstinence from alcohol. As alternative mutual aid SHGs have developed in the past decades, such as Women for Sobriety, LifeRing Secular Recovery, and Secular Organizations for Sobriety, they have also been studied for their effectiveness.

How does the addictions research field get around the voluntary nature of AA in order to conduct randomized trials? A usual sequence of health services for some newly diagnosed alcoholics is to enter professional treatment (which is usually short—a week to thirty days) followed by aftercare, which often means referral to AA or another SHG. The researchers use a treatment population as their subjects, randomly assigning some to the control group, which would receive the usual aftercare (no special referral services), and some to the experimental group, which would receive specially designed services to orient and educate the patients about SHGs before referring them to AA or another SHG. A very large national study, Project MATCH (a government-funded randomized controlled trial and one of best known and definitive outcome studies) used this approach in studying the effects of AA comparatively with the effectiveness of two professionally based treatments (cognitive behavioral therapy and motivational enhancement therapy; Babor & Del Boca, 2003). The experimental condition that connects clients to AA is called 12-step facilitation (TSF); professional clinicians are trained by a manual to explain what AA is like, thereby introducing and referring clients to AA. TSF clients who attended AA did as well or better than those in the two professional therapeutic experimental conditions (Project MATCH Research Group, 1997, 1998). Subsequent researchers built on the idea of having professional clinicians explain AA to clients and more clearly referring them to AA meetings—Kaskutas and colleagues developed MAAEZ (Making AA easier; Kaskutas et al., 2009). Other research designs, such as longitudinal studies or sophisticated statistical procedures (see Humphreys, Blodgett, & Wagner, 2014; Ye & Kaskutas, 2009), are also used.

When the North American psychosocial tradition views SHGs as an alternative human service, a favorite research question involving effectiveness is asked by comparing SHGs to professionals’ therapies and interventions: How is SHG participation similar to and different from professional psychotherapy (e.g., Lieberman & Bond, 1978)?

Another set of research questions pertain to the knowledge used in SHGs—the major internal processes of communication and support that could account for the outcomes or benefits. Researchers recognized early on that sharing lived experience was the major form of knowledge and form of communication, that the meeting process was their key activity, and they explored whether these were associated with or linked to the benefits and outcomes.

Two genres of research on sharing experience in SHGs that developed have been identified: a quantitative “factor” approach and a “narrative” or “storytelling” approach. The following discussion borrows from Borkman and Munn-Giddings (2017). The “factor” genre was originally developed by psychologists inspired by professional group therapy research; the “narrative” or storytelling approach was originally developed by sociologists and linguists using specialized methodologies to study 12-step addictions recovery groups. Both the “factor” and the “narrative” genres have conducted SHG research on an individual or person level of analysis and a group or collective level of analysis.

The quantitative “factor” genre analyzes talk and conversation to identify individual therapeutic factors that measure tasks such as giving help, seeking information, or concomitants of sharing (such as hope) that are likely to be statistically correlated with measures of outcome or with benefits of group participation. Yalom’s (1970) curative factors, derived from the study of professional psychotherapy groups, is the theoretical basis of this work. A wide variety of groups have been studied using the factor approach, such as groups for breast cancer, for those with mental health problems, and for parents grieving the loss of a child. L. F. Kurtz (1997, pp. 18–20) summarized the results of studies showing the five factors most frequently found to benefit participants: helping others, knowing you are not alone with the problem, hope, group cohesiveness, and imparting information.

Specialized measuring instruments have been developed that went beyond Yalom’s (1970) therapeutic factors and were based on the researcher’s intimate knowledge of SHGs. Roberts and her colleagues, as part of Rappaport’s collaborative research with GROW, developed a mutual-help observation system to record the flow of conversation in GROW meetings (see Roberts et al., 1991, 1999). The system consisted of various categories of what they called “Behavioral Interaction Codes,” such as help-seeking, helping behavior, disclosure, questioning, task orientation, or affective response. Observers were intensely trained in the observation system; ten trained observers recorded 527 meetings of thirteen GROW groups, which was determined to be statistically adequate by psychometric standards (see Roberts et al., 1991, 1999).

Early research using the group level of analysis was based on Rudolph Moos’s (1986) social ecological theory of the group’s social climate that affects members’ reactions to the group; standardized quantitative social climate measurements were used. L. F. Kurtz (1997, pp. 41–43), reviewing studies using this genre, found SHGs to be high on cohesion and leader support, to be highly orderly and task oriented (unlike professionally led psychotherapy groups), and to be typically low on anger and aggression.

More recently, other research studies in the “factor” genre have developed quantitative measuring tools based on extensive knowledge of SHGs, using social exchange theory in the United States (see L. D. Brown, Tang, & Hollman, 2014) or, in the United Kingdom, using a specialized national mental well-being checklist (see Seebohm et al., 2013).

The “factor” genre ignored narrative or storytelling, which is the major focus of the second genre. The narrative approach “takes as its object of investigation the story itself” (C. K. Riessman, 1993, p. 1). As Rappaport puts it, “Stories order experience, give coherence and meaning to events and provide a sense of history and of the future” (1993, p. 240). Early narrative studies were mainly conducted on Alcoholics Anonymous meetings using specialized methodologies such as narrative analysis (C. K. Riessman, 1993), linguistic analysis (Jensen, 2000) or discourse or conversation analysis (O’Halloran, 2008; Wooffitt, 2005). Discourse and conversation analysis can be highly technical, having developed elaborate notational systems, such as the Jefferson system, to transcribe verbatim (in real time) the lengths of pauses, all utterances, talk overs (where two people are talking at once), and the like (Wooffitt, 2005). The narrative analysis of sharing in AA meetings has a moderate empirical literature—see Arminen (1998a, 1998b), Cain (1991), Jensen (2000), O’Halloran (2008), and Pollner and Stein (1996), among others. The researchers analyze the structure of interaction (such as norms about turn taking), styles of interaction, characteristics of stories, and the role of humor. AA and other 12-step/12-tradition groups have customs of allowable discourse in meeting, which is summarized as “no cross-talk.” They are listed as “rules” of speech in Mäkelä et al.’s (1996) study of AA in eight countries, and they are the following: Do not interrupt the person speaking; speak about your own experience; don’t profess religious or political doctrines or lecture about scientific theories; speak honestly; speak about personal problems applying the AA program but don’t attempt to refute the program; do not openly challenge previous turns of talk; no direct advice giving; don’t present causal explanations or psychological interpretations of other members’ behavior (pp. 140–141).

*Supportive communities* and *voluntary groups or organizations in civil society*: These two interpretative frameworks are often studied together or by the same researchers. The nature of these phenomena do not lend themselves to positivistic cause–effect paradigms, but rather to more naturalistic paradigms (Guba, 1990; Kennedy, Humphreys, & Borkman, 1994; Lincoln & Guba, 1985) and qualitative methods. However, a variety of cross-sectional and longitudinal designs, case studies, and other designs and methods are used in the application of these interpretative frameworks. The narrative genre is especially widely used by researchers employing these frameworks.

Julian Rappaport (whose work was cited above in the “factor” genre of research) originally studied the SHG GROW as an alternative human service, but found that this viewpoint and methodological approach was limited and did not help him fully understand them. As his collaborative research evolved, he turned to narrative analysis or storytelling as a methodological approach that would demonstrate what he saw about GROW members and their collective that the factor approach would not reveal. Rappaport (1994, 2000) then became especially interested in viewing some SHGs as “normative narrative communities,” where members with serious mental illnesses have a new identity as a member of GROW’s “sharing and caring community” and the formerly dominant psychiatric “patient identity” retreats to a part-time role. As Rappaport (1993) heard in a research feedback meeting with GROW leaders, “they were tired of being asked by doctors to tell bad stories about themselves and … they now saw GROW as doing the best for people when new stories about dealing with today’s practical tasks of living were being told” (p. 251).

In the narrative genre the individual and group levels of analysis are interconnected. On the group level of analysis is the *meaning perspective* (Borkman, 1999a), which is defined as the group’s collectively developed cognitive framework or belief system and values. The belief system includes the following dimensions: how the group defines and deconstructs the focal issue, from its accompanying societal reaction to the issue itself and its causes; how it reconstructs the focal issue in less stigmatizing and more life-enhancing ways; the strategies the group has found that work to solve the issue versus those that do not work; and what the accompanying impacts on and changes in identity are. A parallel concept to *meaning perspective* is Rappaport’s (1993, 1994, 2000) “normative narrative community,” which is similar but expressed as the narratives or stories the group tells about its focal issue and their social identity.

On the individual level of analysis, a number of addiction researchers (Cain, 1991; Jensen, 2000; O’Halloran, 2008; Pollner & Stein, 1996) have explored how telling one’s story as an AA member contributes to the formation of a new identity within the arc of the general AA *meaning perspective*. As Cain (1991) said, “The AA story provides a general framework, of which the individual stories are specific examples” (p. 227). As an AA newcomer becomes a committed member, stops drinking alcohol, and changes other behaviors and attitudes, their story and identity evolve to become an individualized version of AA’s *meaning perspective* or “normative narrative community.” The narrative genre also addresses topics such as how storytelling creates mutual aid in meetings (Arminen, 1998a, 1998b).

Other addictions researchers using the supportive community framework employ the factor approach by questioning participants on items revealing supportive or unsupportive relationships. An example is mentioned here, but the findings are reported in Subsection 3.3. Laudet et al. (2000) studied the dual-diagnosis group Dual Trouble in Recovery, which helps individuals with both mental health and addiction issues; they assessed social and spiritual support for recovery with items answered on a four-point Likert-type scale. Their items included options like the following: (negative support) “no one in my life really understands me“ and (positive support) “my friends are encouraging/supporting me” (Laudet et al., 2000, p. 15). An example of a spiritual support item was “My relationship with my Higher Power contributes to my sense of well-being” (p. 4).

Researchers from the European psychosocial tradition are more likely to study the impact of SHGs on civil society (Chaudhary, Avis, & Munn-Giddings, 2013) and to view them as voluntary organizations or supportive communities. Section 4 of this article is more in that tradition, looking at the governmental, human service, and civil society contexts in which various SHGs develop and how that affects their nature and relationships with others.

Researchers examining SHGs as voluntary membership organizations tend to use case study designs, which is typical and conventional in SHG research. But the cross-cultural research shown in Case Illustration 8 is relatively rare and, as you will see, not without its difficulties.

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Case Illustration 8

Lessons Learned in Cross-Cultural Research with SHOs

by Carol Munn-Giddings and Thomasina Borkman

This illustration of cross-cultural research involves case studies of mental health SHOs in the United States and United Kingdom viewed from the perspective of voluntary membership organizations in the third sector. We present some difficulties and complexities of doing interdisciplinary cross-cultural research that were mostly unanticipated.

Increasingly, third-sector studies have attempted to expand our understanding and knowledge base of the third sector and civil society through the situating of voluntary organizations and activities in their historical and sociopolitical context. This type of scholarship has embraced comparative studies of phenomena based in different cultural and/or country contexts (Salamon et al., 1999). However, little literature to date has explored these aspects in relation to SHGs or their offshoots or in qualitative studies.

Having collaborated on research for several decades, we—Borkman (United States) and Munn-Giddings (United Kingdom)—have become increasingly aware of the importance of cultural contexts in shaping our approach to research. Here, we reflect on some core issues we think are helpful for other self-help researchers to consider in their research processes, focusing on a cross-cultural study of SHOs we undertook from 2002 to 2004.

This case illustration pertains to the US and UK experiences. We explored mental health SHOs, identifying how they were organized; what services they provided; what self-help/mutual aid was done; and in what health, welfare, and policy contexts they operated. We used case study methodology with a participatory design involving observations, semistructured interviews, and feedback sessions. Two SHO cases were written up for each country (see Borkman, Karlsson, et al., 2005). In the United States, a sample of SHOs from one state that were affiliated with the same umbrella organization were contrasted with each other; while both were registered, formal nonprofit organizations, Just Us behaved like a regular supportive small SHG while the other, Promise, for the homeless mentally ill, operated almost like a bureaucracy with many linkages to mainstream services. In England, where there were few mental health SHOs, two organizations in different areas of the country were selected. Lifecraft was open 365 days a year, exemplified mutual aid, offered a loving environment, and was distinctive for “normalizing” mental illness by allowing flexible working patterns for paid staff. The other organization, the Nottingham Advocacy Group, has a name that reveals its primary mission; it was not a service organization.

We had chosen mental health SHOs because we had identified through our previous research broadly similar organizations operating in both countries and originating from similar social movements (it is worth noting that Oka and Chenhall [2007] had written that the same name can denote quite different organizations in different cultures).

Terminology:Although we adopted the term *self-help organizations* (SHOs; a term more widely used in the United States), “user-led organizations” (ULOs) is much more commonly used in the United Kingdom. In addition, in the United States, the terms “mental patient” and “mental hospital” are still widely used, but they would be considered retrograde or even abusive in the United Kingdom, where the mental health service-user movement considered these terms to be part of the medical labeling they strived to overcome (Thornicroft, Rose, & Mehta, 2010). In the end we looked to the service-user/consumer movements in both countries for the terms they used. It was not an easy issue to resolve, as we could not simply adopt the language of one country without being sensitive to its understanding in another.

Participation in the research process:We were committed to doing participatory research in which the service-users/consumers (who were the people of interest in the research) would be involved in various phases of the research, but we did not understand when we designed the study that we—as in Borkman and Munn-Giddings—understood different things by “participatory research,” nor that both the policy context and expectations of service users might vary so significantly between countries.

Our experiences of this stage of the process were quite different. For example, the efforts of the US researchers to involve the participants in the research were often met with indifference; however, it should be noted that the researchers had initially presented themselves as supporters of SHGs and SHOs with extensive histories of studying them constructively. In the United Kingdom, there was a comparatively heightened awareness among mental health service users of the “rights” of participants to get involved at different stages of the research process. These differences impacted the way in which data was collected, and maybe also the type of data collected. Issues of trust in the researcher and, in particular, the impact this has on access were also noted by Mäkelä et al. (1996, p. 267) and Chesler, Chesney, and Gidron (1990, p. 261).

Ethical approval processes:Constituting another factor in the process that we had underestimated that affected comparability were the ethical approval processes. Ethical research review boards had different criteria for participatory research: In the United Kingdom, the study was eligible to go through the University ethics committee, where many panel members were experienced participatory researchers themselves. At the US university, the Institutional Review Board was very medically oriented in all research dealing with mental illness and health, and our study was regarded with suspicion.

Analysis and presentation:Researcher training and specialty differences of which we were unaware affected the ways we conducted the research, especially in terms of data analysis and the development and writing up of the case studies of each SHO. Borkman had been trained in the 1960s in a positivistic tradition in the sociology department at Columbia University in the United States, with a specialty in organizational analysis. Munn-Giddings had been trained in a more qualitative and participatory research tradition in the 1980s in the United Kingdom, with extensive professional experience teaching and conducting participatory research with service users in community and health care contexts, where work with different stakeholder views is common. The differences in specialty, training, and orientation led to noticeable differences in the way that the data for the case studies were initially written up; for example, Borkman interviewed each position in the hierarchy individually, whereas Munn-Giddings interviewed them in a room together at the same time. This produces large differences in information about the organization.

Methods of working:Our research team was multinational, cross-discipline (sociology, social work, and applied social science), and composed of experienced researchers with their own idiosyncratic ways of working evolved over many years of practice in the field. The latter point is not to be underestimated, as there is an understandable tendency to attribute differences in style or approach to one’s discipline or one’s country’s tradition, but reflective conversations also revealed that these differences might equally lie in a researcher’s preferred way of working—usually because they see it as most effective in their own setting. To challenge “the familiar” is a difficult thing to do (Winter & Munn-Giddings, 2001), but also essential if we are to develop our practice. Our collaboration was unusual in that researchers from one country were involved in the fieldwork of another—this we think exposed the assumptions and limitations to comparability in our study that might otherwise have remained hidden.

We would argue that our primary unit of analysis—an SHO—was similar enough in both countries to bear comparison for similarities and differences both within and across cases. Our research tools (instruments) had an equally strong common core, which meant we could compare our data within and across countries. The primary differences were located in the research process itself, due to implicit “assumptions” we made, our range of disciplinary and personal approaches, ethical approval processes, and the differing expectations of participants in the research study. These process issues are often obscured in final accounts of research projects, but transparency is crucial if we are to develop our practice in this area. Some issues could have been resolved in early stages of research if we had detected them; here we may have been hampered by lack of funding and, consequently, a paucity of face-to-face meetings. Others could not have been resolved—for example, the different expectations of participants. These were culturally, not methodologically, determined.

The above highlighted that we needed to understand the broader contexts (health care system, mental health policy, user movements, and third-sector position) in which we were working and the impact they might have on the research process. Consequently, as we have developed our research further, we have become very wary of authors who write in universalistic terms as if the country and its health and welfare systems were irrelevant (Borkman & Munn-Giddings, 2008a, p. 146). See Section 4 by Munn-Giddings and Boyce for a fuller discussion of the importance of the social, cultural, and political contexts that shape SHGs, SHOs, and their accompanying research base.

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Collaborative research and participatory action research (PAR) are complementary approaches to establishing relationships with the “subjects” of one’s research and converting them into co-researchers willing to maintain their involvement and cooperation in implementing the research over a long period of time. The North American psychosocial researchers have been adept at developing both approaches.

The field of community psychology advocates that researchers need to step away from their universities and conduct their research and action in collaboration with and in the settings of the community-based organizations and individuals that they seek to assist (Davis et al., 2006). As a sociologist I was trained to conduct field research in this manner. Collaborative research with community-based organizations is one strategy community psychologists and others use, which involves shifting from the role of detached observer and expert to those of facilitator and co-researchers (Rappaport & Seidman, 2000). Collaborative research is not a particular method; it draws on quantitative and qualitative designs and methodologies. What distinguishes it from other research approaches is the “integral link between the researcher and the researched whereby the concepts of cultural humility and cultural safety are combined with process methods and procedures (such as group facilitation) to establish and maintain the research partnership” (Israel et al., 2005, p. 12).

Collaborative research overlaps extensively with action research and participatory action research, the latter two approaches originating from fields other than community psychology. All three have been used and developed further as methodological approaches by self-help/mutual aid researchers; by 2004, the three concepts were almost used interchangeably in the literature. Action research emphasizes research with community-based groups that leads to social learning and change (Lavoie, 1984); participatory action research (PAR) is similar, but highlights having the “subjects” of the research as co-researchers and sharing power with them in terms of research goals and design and the process of collecting and analyzing data (R. R. Taylor et al., 2004); in some cases the professional researchers are also members of the SHG or its offshoot (see Chesler, 1991b; Mankowski, 2014). The values and perspectives of SHGs and their spinoffs and offshoots often coincide with and are congruent with the PAR approach, especially in terms of emphasizing the values of empowerment, supportive relationships, social learning, and social change (Nelson et al., 1998).

Several notable collaborative action research projects with SHGs, their spinoffs, and offshoots have been conducted, three of which will be mentioned: (1) Julian Rappaport et al.’s (1985) long-term relationship with GROW, an SHG for people with severe mental health issues; (2) the project of the Self-Help Network of Kansas to maintain and conduct research on their statewide database of SHGs (excluding AA) into the 1990s (Wituk et al., 2000), which then changed with the times to support mental health consumer/survivor-run organizations (see L. D. Brown & Wituk, 2010); and (3) the nearly twenty-year collaborative relationship between the offshoot ManKind Project and academics at different universities who themselves might be ManKind Project participants as well as researchers (see Mankowski, 2014). The ManKind Project is a mutual help organization for men to address challenges they experience as gendered beings by providing peer support for reconceptualizing and transforming their conventional sense of masculinity (Mankowski, 2014, p. 34). A distinctive aspect of this research is the researchers’ awareness and articulation of the advantages of having researchers who are inside participants as well as researchers with outside perspectives (Mankowski, 2014, p. 35).

Two other participatory action research projects that are distinctive will be mentioned in more detail. An unusually long-term and fruitful collaborative relationship has been between De Paul University and a spinoff of AA called Oxford House. Oxford House is a community-based, peer-run, residential housing substance abuse recovery program whose standards are promulgated and maintained by a centralized nonprofit organization led by one of the spinoff’s cofounders. In 2006, the research partnership was thirteen years old when Leonard Jason, Ferrari, and other De Paul community psychology faculty and graduate students published the book *Creating communities for addiction recovery*; now, in 2020, fourteen years later, the partnership has thrived for twenty-seven years. Several generations of graduate students have been trained and become mid-level professionals through participating in this research. Further, some Oxford House residents who were employed as research assistants later graduated from De Paul University as researchers with dual roles. These researchers have been flexible, studying Oxford House using all three frameworks over the twenty-seven-year period; it would be interesting if we knew how researching self-help/mutual aid over the years may contribute to opening the mind and heart of the researcher.

The Canadian partnership for mental health recovery and transformation of the professionally based mental health system constitutes a decades-long offshoot: The provincial government of Ontario worked with mental health consumer/survivor initiatives, in some cases funding start-ups or helping sustain others, as well as with academics at Wilfred Laurier University (see Nelson, Lord, & Ochocka, 2001) and others. Geoff Nelson and colleagues use participatory action research in working with the Ontario Peer Development Initiative (OPDI), an umbrella organization of over fifty-five mental health consumer/survivor initiatives (CSIs). Nelson et al. (2010) emphasize the importance of power sharing with the consumer/survivors for an equitable and constructive partnership; especially important is that “the experiential knowledge is valued equally with that of professional knowledge” (p. 44). They tend to view CSIs from a human service perspective, perhaps because they are working from within the system to change the mainstream institutions.

Collaborative approaches, the ideal of power sharing, and participatory action research are not, however, always conflict-free. Daryl Isenberg, long associated with the Chicago Self-Help Clearinghouse, and colleagues (Isenberg et al., 2004) interviewed twenty-five self-helpers from seventeen SHGs or support groups and found that self-helpers gave instances of both negative and positive experiences with collaborating on research. On the negative side, the self-helpers found the following: (1) they did not always have the same research objectives as the researchers; (2) trusting working relationships were not always developed; (3) exploitation by the researchers occurred in six of twelve cases by misrepresenting their research, failing to give proper credit to the SHG, using information without permission, or trying to change program elements for research purposes; (4) some self-helpers failed to see the value of research and saw it as an unwelcome burden or irrelevant, as they felt anecdotal testimony was sufficient evidence of effectiveness; (5) unwelcome constraints due to university rules and procedures. Positive experiences were also recorded that included the following: developing similar research objectives; working with researchers who had personal experience of the focal issue of the SHG; some positive experiences from having the results of the research disseminated; and, especially important, that some self-helpers learned how to do research through the collaborative relationships (Isenberg et al., 2004, pp. 131–132). Dr. Caroline Kaufmann, a well-trained researcher and a mental health consumer/survivor, conducts research on CROs (see Kaufmann, Schulberg, & Schooler, 1994), and is representative of many principal researchers of the demonstration projects of mental health consumer/survivor organizations (Clay, 2005).

Actually, England, with its national health policy of extensive patient participation, is far beyond the United States in teaching self-helpers how to do their own research. Carol Munn-Giddings, coauthor of Section 4, has had varying experiences with this, such as teaching older citizens how to conduct research on and about their age group (Munn-Giddings, McVicar, et al., 2009, 2016) and supporting research where young people are involved in all stages of the research process (see, for example, O’Brien, Moules, & Munn-Giddings, 2018; Törrönen et al., 2018) The experiences of cross-cultural research (just as in collaborative research) always reveals more than is obvious, and can lead to nuanced findings and guideposts for future collaboration.

## 3.3 Inside the Rooms

The title of this subsection, “Inside the Rooms,” is adapted from the saying “In the Rooms” in 12-step groups that refers to being a member, attending meetings, and being involved in the self-help/mutual aid process. It considers three issues: First, who goes to SHGs, gets involved, and participates? What are their demographics? Second, what are the internal dynamics of meetings and the mutual aid processes that link individuals to the group, and what are the mechanisms of individual change? What are the major results of participation, such as benefits and outcomes? Third, what are major spinoffs and offshoots that have arisen from the self-help/mutual aid movements? These issues are addressed by briefly considering related research and their findings, especially from the 1990s and later.

Section 2 sketched the key elements of contemporary SHGs as found by the research. These included developing the sharing circle meeting of lived experience, the ethos of mutual aid, and the centrality and significance of giving help to others. These foundational elements were the overlapping part of the histories of three distinct health social movements: Alcoholics Anonymous, the general self-help group movement, and the mental health consumer/survivor movement. By the time of their institutionalization in 2000, the three movements had diverged and gone in different directions. AA and the alternative addiction SHGs (such as Narcotics Anonymous, Cocaine Anonymous) have mostly maintained their fidelity to the original SHG model, especially because the 12-step/12-tradition form of small group has been successfully structured to withstand professionalization, bureaucratization, or the iron law of oligarchy. Women for Sobriety (WFS), LifeRing Secular Recovery, and SMART Recovery have also maintained a small-group structure, perhaps partly in competition with the 12-step groups.

The general self-help/mutual aid group movement (consisting of the widest array of illnesses, disabilities, diseases, conditions, stigmatized social statuses, and family groups for many of the addictions) have the widest variety of organizational forms—self-help groups, hybrid groups of peers and professionals, and self-help organizations. The issue of the extent, kind, and dependence on direct professional involvement is very salient. In contrast, the mental health consumer/survivor movement, through its vigorous and successful political action, succeeded in becoming a partner with the mainstream health care system; governments now fund many mental health consumer/survivor run organizations (CROs), and a state-based training and credentialing system has been established to provide mental health peer supporter specialists with opportunities for paid employment in mainstream mental health agencies. The power and control of professionals, which is exercised through being in charge of funding requirements and the training, credentialing, and supervising of peer support specialists, is more indirect. CROs are required to be legally registered nonprofit organizations, making them hierarchical and far removed from the basically egalitarian structure of an SHG. In other words, the mental health consumer/survivor movement and its version of peer support have abandoned their mutual aid structures and capitulated to indirect government and professional control; as such, I regard the CROs and mental health peer support specialists (and people with equivalent titles) to be offshoots of self-help/mutual aid, rather than instances of self-help/mutual aid per se. They have become so different that to regard them as being of a piece with the 12-step/12-tradition small groups that still proliferate and that allows the key elements of SHGs to flourish would confound research. Mental health CROs are briefly mentioned in Subsection 3.4, but are not covered in this subsection.

### 3.3.1 Who Participates in SHGs and What Are Their Demographics?

Relatively few people who are eligible to participate in an SHG actually do so. The proportion of potential members who have the focal condition of the group who actually participate is estimated to be in the range of 4–20 percent. Available data are sparse and often somewhat questionable because of the lack of adequate samples on which to base the numbers. There are some indications that those in greater distress or who have more severe symptoms are more likely to try an SHG (Humphreys, Avis, & Stöffelmayr, 1991; Kelly, Magill, & Stout, 2009; Medvene et al., 1994). There are few studies of many local groups of one specific kind of SHG that describe the demographics of who participates (one that does is the study of Candlelighters groups for parents of children with cancer; Chesler & Chesney, 1995). There are probably more studies on AA and the addictions recovery groups than the general SHGs, especially since research on the latter has slowed to a trickle in comparison with the large ongoing output of addictions recovery research. This subsection will briefly examine the sparse research on gender, racial and ethnic minority participation, gay self-helpers (in AA), and the issue of spirituality or religion in 12-step SHGs.

The conventional wisdom is that SHGs are a white, female, middle-class phenomenon, but that idea needs to be questioned on several counts. First, observers are often looking at selected parts of the SHG universe, such as general self-help groups, but excluding AA and NA (Narcotics Anonymous), which are 60–70 percent male and a huge part of the SHG world. Humphreys, Avis, and Stöffelmayr (1994, p. 178) point to the perspective of the professional observer, who is likely to be in a White, middle-class area with a limited view. Another issue is that so many SHGs are local, and there are inadequate lists on the national level from which one could identify representative or geographically based samples. Accordingly, it is very difficult to know the gender, racial and ethnic composition, or socioeconomic status of the members of many SHGs.

A review of research on SHGs for men (Mankowski & Silvergleid, 1999) revealed a surprisingly larger number of groups than one might expect, for both health and social issues such as impotence, prostate cancer, circumcision, substance abuse, domestic violence and battering, or fatherhood; there is also the ManKind Project for men as gendered beings, focusing on considering their socialization (particularly in light of the vast changes in women’s roles related to the women’s movement over the past half-century). Mankowski and Silvergleid (1999, p. 287) agree with the conventional wisdom that the majority of men who participate in SHGs are White, well educated, middle or upper class, and heterosexual.

Research focusing on women in SHGs has been done primarily about women in AA or other substance abuse SHGs. A major review (Ullman, Najdowski, & Adams, 2012) was very thorough in its search of major online databases, including Dissertation Abstracts International. The reviewers looked at research on help-seeking and then at research on affiliating and commitment among those who attended AA. In both cases, few studies focused on the help-seeking, affiliating, or commitment of females compared to males; the results in both sets of studies were inconclusive. Where research outcomes were concerned, “the few studies that do show significant gender differences tend to suggest that attending AA results in less drinking and more abstinence for women than for men” (Ullman, Najdowski, & Adams, 2012, p. 454). Women may also have fewer alcohol-related deaths than men (p. 454). Another interesting finding was that women who were survivors of sexual assault were likely to attend more AA meetings than women AA members who were not such survivors (p. 470).

Several other sets of studies on women are noteworthy:

Kaskutas (1994) studied all available Women for Sobriety (WFS) groups. WFS members who also attended AA were more likely to get sober and had fewer relapses than women who attended WFS only; this is consistent with other studies that showed that women who obtained additional help instead of relying solely upon AA had more sobriety (Kaskutas, 1994, p. 459).

Regular surveys by AA of a sample of its groups, conducted every two to three years, show that from 1974 to 2004 about a third of its members were consistently female (Kaskutas, Ye, et al., 2008). In the most recent survey I could find, dating from 2014, 38 percent of members were female (AA, 2014). A recent study (Zemore et al., 2017) compares the demographics of females and others between 12-step groups and alternate SHGs like WFS, LifeRing, and SMART.

Zemore et al. (2018) conducted a large national online survey of individuals with a lifetime alcohol use disorder (AUD) who were members of a primary addictions recovery SHG (and had attended an in-person meeting within the last thirty days). They named the study the PAL study for Peer ALternatives in Addiction and recruited from in-person meetings and online announcements at LifeRing, WFS, and SMART; for 12-step groups they recruited from an online platform, In the Rooms, where they successfully recruited participants from AA, NA, Cocaine Anonymous, Marijuana Anonymous, and Methadone Anonymous. This is the largest comparative study of the 12-step groups and the three alternatives (ALTs; total *n* = 701).

Demographically, the participants in all four SHGs (the 12-step groups counting as one SHG) were similar in being primarily white and very well educated (27–35 percent had postgraduate training or degrees) with substantial female representation (12-step groups 68 percent [*n* = 208]; WFS 100 percent [*n* = 177]; LifeRing 38 percent [*n* = 99]; SMART 40 percent [*n* = 167]). Participants in the ALTs were less religious and higher in education and income than the 12-step participants. The modal self-identification of each group as either religious, spiritual, agnostic, or atheist is revealing: 52 percent of 12-step members and 48 percent of WFS members chose “spiritual” while 40 percent of LifeRing members chose “atheist,” and SMART members were split—30 percent agnostic and 30 percent atheist. Zemore and colleagues thought that highly educated secular individuals were more likely to choose the ALTs because they emphasized cognitive–behavioral ideas (i.e., scientifically informed) in contrast to the spiritual and religious emphasis of the 12-step groups.

ALT participants attended fewer meetings a week (and there were fewer from which to choose than the 12-step meetings), but they engaged in as many other activities within the groups—such as service work and leading meetings—as the 12-step participants. The 12-step participants had the highest percentage of people with five or more years of being clean and sober. Those whose primary group were either 12-step or WFS had a higher percentage of people endorsing total lifetime sobriety, the most stringent abstinence goal, which is statistically associated with longer sobriety.

The criticisms of feminists and others that AA is male-dominated, sexist, patriarchal, and therefore damaging to women was a major issue addressed by Sanders’s research, reported in her book, *Women in Alcoholics Anonymous: Recovery and empowerment* (2009), and was an issue considered in several qualitative studies described by Ullman, Najdowski, and Adams (2012). The four qualitative studies found that women attending AA agreed that the language of the major texts was indeed sexist, with male God images, but they did not have a significant problem with it. A major reason may be the widespread use pattern among women participants in AA of attending women-only meetings where women’s empowerment is emphasized (Sanders, 2009).

Sanders considers two polar opposite beliefs among feminists: Whether AA is disempowering or empowering to women members. Elaine Rapping’s (1996) *The culture of recovery* represents the argument that AA is disempowering for women because the model of AA focuses on personal development rather than achievement for women; the model encourages women to view themselves as the problem rather than organizing themselves to change the sociopolitical environment. On the other side are the feminists who view women as active participants in developing a feminist culture within AA and the recovery movement. “Feminist analysts of this school view AA and the twelve-step movement as primarily a therapeutic exercise, which has been very successful in helping women psychologically in terms of emotional and behavioral health,” Sanders says (2009, p. 12).

Sanders’s sample consists of the women attending women-only AA meetings in one metropolitan area; there were twenty-seven such meetings, from which 167 women completed the survey. Sanders used some feminist questions as well as questions on religion, belief in God, and use of prayer from the latest General Social Survey and US Census data so she could compare her sample to women in the general population. In terms of age, race, marital status and employment, Sanders’s sample is like women in the general population who drank heavily. The sample differs in being highly educated (70 percent were college graduates or more), with high personal incomes, and with disproportionately high-prestige jobs, such as in professional, technical, managerial, or administrative fields.

The AA women were more feminist than the general female population: 52.2 percent of AA women self-identified as a feminist in comparison with 28.7 percent of the general female population, and 94.4 percent of AA women thought that the feminist movement had improved their life while only 47.2 percent of the general female population felt that way. Sanders found that her sample used other help in addition to AA, were involved in improving their relationships with other people and learning to become self-protective (instead of self-destructive, as when they were drinking), and attended other 12-step programs. She concluded that they were both producers and consumers of AA because they brought back into AA ideas from other 12-step programs, and they utilized the steps and other aspects of the program to stay sober and to grow emotionally and spiritually. Sanders (2009) argues: “For all of these women building self-esteem and learning what is emotionally healthy leads to empowerment. This is the language of empowerment that has evolved over time within the twelve-step movement” (p. 130). Sanders concludes that “the findings in this study do not support the criticism that AA and the twelve-step community influence women negatively in terms of feminist empowerment” (p. 130).

Racial and ethnic minorities are thought to be underrepresented in the type of SHGs defined in the present literature review (Gutierrez, Ortega, & Suarez, 1990; Neighbors, Elliott, & Gant, 1990). Information about their representation in AA is available from AA for the years 1996, 1998, 2001, and 2004: During that time, Black people constituted 5 percent of total membership except in 2004 when the figure slipped to 3 percent, while Hispanic membership kept steady at 4 percent through those years (Kaskutas, Ye, et al., 2008, p. 265). In the most recent survey I could find, dating from 2014, Black people constituted 4 percent of total membership while Hispanics were 3 percent (AA, 2014). In large cities with substantial Hispanic populations, Hispanic self-helpers have their own network of Spanish-speaking AA meetings. Hispanic AA members, many coming from Mexico to the United States, brought with them a Catholic-based, Latin American culture, which adapted the egalitarian buddy system typical of AA in the United States into a vertical, hierarchical, “godfather” (*padrino*) system (Munn-Giddings, Oka, et al., 2016, p. 396).

Neighbors, Elliott, and Gant (1990) explain the lack of participation by Black people in single-issue SHGs (as defined here) as due to their more pressing need to deal with racism. They define Black self-help as building institutions (without the help of mainstream society) to make economic and developmental progress against racism in a hostile society. They point to many politically active voluntary organizations and action agencies such as the NAACP (National Association for the Advancement of Colored People) and the Urban League, as well as other institutions—Black colleges and universities, businesses, and so forth. They argue, similarly to the argument that Gutierrez, Ortega, and Suarez (1990) make about Latinx underrepresentation in SHGs (which will be discussed later), that if self-help/mutual aid were defined more broadly to include churches and other forms of voluntary organizations, then Black people would be fully represented. The underrepresentation of Black people in the type of SHGs defined in this review was also found in Lieberman and Snowden’s (1994) study based on the California Self-Help Center’s comprehensive database of single-issue SHGs; they estimated Black membership was 0.4 percent when the Black population in California was then 7.4 percent.

One single-issue SHG for Black people—for sickle cell disease—is found in the North American psychosocial literature (see Nash & Kramer, 1994). Nash and Kramer conducted a five-year, multistage study of sickle cell disease SHGs, beginning with locating where the groups were and finding out their composition. In 1994, 134 groups were known to exist in 31 states, the District of Columbia, and one province in Canada (Nash & Kramer, 1994, p. 213). They did four additional studies both of parents in groups and of adolescents with the disease in various groups (Nash & Kramer, 1994, p. 214). They found that group members were more likely to be of lower income but higher educational levels than comparable Black populations more generally (p. 222). Longer-term membership was associated with more positive psychological benefits and fewer hospitalizations, but not a lower incidence of physical symptoms (which was attributed to the fact that sickle cell disease is a genetic disorder).

One study was found that compared culturally specific women’s breast cancer groups for Black, Latina, and White women in Florida in 2007–2009 (Corvin et al., 2013). Two groups from each ethnic and racial category were studied; the researchers followed a procedure for determining what a group viewed as the key elements of a breast cancer self-help support group. Groups were then compared to see if they each envisioned the same or a different cultural model of a breast cancer self-help support group. The researchers found that the same cultural model held across Black, Latina, and White groups. However, the Black and the Latina groups independently reported preferring to attend culturally specific groups like their own; there were subtle differences in emotional expression and styles of communication that they referred to as important, and for Latina groups the Spanish language was important as well.

Given the historical variation in how scholarship has referred to Spanish-speaking people and people of Latin American origin, they are variously called Latinos or Hispanics in SHG research, and there has also been research on Mexican Americans. Latinx people are found in the general population to have low utilization of human services and very low representation in mainstream SHGs such as AA, Parents Without Partners, and the like; however, if self-help/mutual aid were defined more broadly to include churches, family groups, and ethnic associations, then Latinx people would be better represented (Gutierrez, Ortega, & Suarez, 1990, p. 218). Part of the reason for the lack of Latinx representation in mainstream SHGs are cultural differences, including those of language, family, and religious orientation. Gutierrez and colleagues suggest that mainstream SHGs could develop culturally appropriate chapters for Latinx people, and specifically mention the National Alliance on Mental Illness (NAMI), which is for family and friends of individuals with mental health issues.

Gay and lesbian self-helpers are rarely mentioned in any of the research traditions. One noticeable exception is a book by Audrey Borden titled *The history of gay people in Alcoholics Anonymous* (2009), which plots the painfully slow progress of gay people in AA toward gaining respect, feeling included, and being identifiable through their own special purpose meetings. Interestingly, the first female member of AA, Marty Mann, was later recognized as lesbian, and her partner also joined AA. Borden chronicles the timeline of main events, such as the early development of gay and lesbian groups in large cities (Boston, New York, San Francisco, Los Angeles), their early secrecy, and their difficulty obtaining recognition within AA (such as the ability to be listed as gay and lesbian groups in directories or to have educational pamphlets about gay and lesbian members in AA). The American Psychiatric Association removed homosexuality from the *Diagnostic and statistical manual of mental disorders* in 1973. In 1974, the AA governing body of representatives of AA voted to include gay and lesbian groups in its World Directory (Borden, 2009, p. 7); by 1975, seven US cities had a gay or lesbian AA group, a figure that increased to 225 cities by 1985, and to 311 cities by 1990 (Borden, 2009, p. 8).

A final aspect of the participant characteristics of addictions recovery groups is religiosity or spirituality, which was briefly discussed in the findings of Zemore et al.’s (2017) PAL study. The addictions recovery SHGs are primarily where the issue of religiosity or spirituality surfaces, since the 12-step groups describe themselves as “spiritual but not religious.” Nonetheless, US courts have ruled them as religious, and it is unconstitutional for judges to require someone to attend a 12-step group without providing them with an alternative (such as an alternative addictions SHG or going to jail; Hedblom, 2007). The alternative SHGs (Secular Organizations for Sobriety [SOS], which evolved into LifeRing Secular Recovery and SMART Recovery, regard alcoholism as a bad habit, not a disease) were founded in opposition to the religiosity/spirituality of the 12-step groups; Women for Sobriety (WFS) was founded in reaction against the male patriarchal nature of AA in the 1970s, but explicitly endorses spirituality, not religion. Several studies have shown that 12-step members self-identify as religious or spiritual, whereas LifeRing and SMART participants are more likely to be anti-religious and anti-spiritual, if not agnostic or atheist (Atkins & Hawdon, 2007). Such self-identifications were confirmed in the recent PAL study, where a majority of 12-step participants described themselves as spiritual (53 percent)—a proportion similar to WFS participants (48 percent)—in comparison to the minority of LifeRing (21 percent) or SMART (24 percent) participants who identified this way (Zemore et al., 2017, p. 22). Studies of agnostics and atheists who do participate in AA show that they do as well as other AA members (Kelly, Magill, & Stout, 2009). The PAL study found some agnostics and atheists among the 12-step participants (18 percent and 4 percent respectively) and among WFS members (23 percent and 11 percent). There are AA meetings for atheists listed in large cities such as New York City. Agnostics and atheists in AA recently published a book (Roger C., 2014) in which they express their hope of increasing their acceptance within AA; they also express their concern about minimizing dogmatism and allowing freedom of expression as the cofounders and original groups intended. Their struggle is reminiscent of the battles endured by gay and lesbian members in AA (see Borden, 2009).

### 3.3.2 Participating in the Group, Dynamics of Change, and Resulting Benefits

This subsection pertains to participating in and engaging with the group, and the dynamics of change and the resulting benefits or outcomes. First, what is the impact of individual participation in and engagement with an SHG? How are participation and engagement conceptualized and measured? Second, what theories or explanations account for the mechanisms of change whereby participation leads to benefits or outcomes? What are the differences, if any, in the ways the psychosocial and addictions recovery research traditions conceptualize and approach these issues? What empirical research has been done in the two traditions to show how mechanisms of change are linked with benefits or outcomes? Finally, what are the downsides and “dangers” of SHG participation?

The addictions recovery tradition is a positivistic model trying to establish cause–effect relationships while the psychosocial tradition is more interested in understanding a phenomenon; consequently, the traditions produce dramatically differing interpretative frameworks of human agency. When SHGs are viewed as a form of human service by the addictions recovery tradition, the group characteristics are viewed as the mechanisms of change that then lead to individual outcomes. The individual is implicitly seen as being acted upon by these group dynamics. Helping others, interacting with new sober relationships, and engaging in the program (by reading its literature, having a sponsor, working the steps in 12-step programs, etc.) are components of mechanisms of change. In contrast, the psychosocial tradition, which views SHGs as voluntary organizations or supportive communities, is more likely to use the language of “benefits” rather than “outcomes” and to view members as helping to create their own benefits partly through their length of participation and intensity of involvement with the SHG. Member participation contributes to group survival, group cohesion, and other group characteristics, which in turn benefit the individual. Expressed in a slightly different way—SHGs do not exist apart from their members, who are both the intervention and the object of the intervention (Finn, Bishop, & Sparrow, 2009).

Turning to the issue of how the research traditions conceptualize and measure the extent of participation and engagement in the group, large differences are found. Researchers in the psychosocial tradition may ask about the number of meetings attended and length of participation, but often not much more than that. However, many of the SHGs they study, such as bereavement groups, groups for transitions such as divorce or breastfeeding, or some illness groups, expect relatively short-term levels of participation, usually for a year or two (Borkman, 1999a). Analyses of data may not even be done by length of attendance, but when they are, they usually find more benefits accruing with longer length of attendance (Nash & Kramer, 1994; Raiff, 1984).

Two exceptions are noteworthy, both conducted with GROW members. Roberts et al. (1999), as part of their collaborative research over time with GROW in Illinois, used a specially developed Behavioral Observation System to have trained researchers observe meetings and record members helping others and being helped, members’ information exchange, and so on. It was a rigorous study that did not depend upon self-reports, so members were also surveyed six to thirteen months later about their perceived benefits. Those who had helped others (change dynamic) had improved psychosocial functioning (benefit). Those who had experienced a high degree of group cohesion and closeness (change dynamic) improved in social adjustment (benefit), whereas those not experiencing group cohesion made no such improvements.

Finn, Bishop, and Sparrow (2009) did collaborative research with Australian GROW members (GROW originated in Australia in the 1950s, adapting AA’s 12 steps and practices for persons with serious mental illness). Using observational data collected by researchers of GROW meetings over a three- to six-month period and phenomenological interviews with twenty-four GROW members (63 percent of whom had belonged to GROW for more than five years), they found such striking changes as individuals changing from a passive stance to an active one where they took responsibility for their actions; helping others; becoming part of the community; feeling useful, valuable, and accepted by others; and experiencing an identity transformation. Learning by doing was a trademark!

The much larger addictions recovery research literature (primarily about AA) has developed more measures of participation and engagement, an array of scales of affiliation or involvement, and a number of sophisticated analyses. While longitudinal studies of six months or a year are most frequent, a few longer-term studies of two, three, or even five or seven years are found.

Kaskutas, Ammon, et al. (2005) identified a sample of self-helpers when they were still in treatment and followed them for five years, noting their attendance at AA; they found four types of AA careers based on patterns of attendance at AA meetings. Interestingly, lack of attendance was not assumed to be disengagement with AA, which was separately measured. They found that half of those in the *declining* pattern (frequent attendance during year one that declined significantly by year five) and a third of those in the *low* pattern (regular attendance only in the first year after treatment was completed) felt like they were AA members (Kaskutas, Ammon, et al., 2005, p. 1983).

Various conceptualizations and measurements of AA’s 12-step practices and spiritual beliefs have been used in addictions recovery research. A single 12-step form of engagement is measured, such as “having a sponsor” who is a more seasoned member able to role model practicing the 12 steps and engaging in the program (Witbrodt et al., 2012). Twelve-step practices can include helping others, reading the literature, or working the steps. Morgenstern et al. (2002) chose to measure belief in a Higher Power, commitment to abstinence, and commitment to AA, among other measures, while Zemore and Kaskutas (2004) envisioned spiritual practices in terms of measures of Theism (i.e., measures of experience of God in one’s life) and Self-Transcendence (i.e., a feeling of connection with others and the universe). Summarizing these and other efforts, Kelly, Magill, and Stout (2009) think that the conceptualization of spiritual practices has been complex and inadequate.

Reviewing the relatively large amount of research in the two traditions on the issue of conceptualization and theories of the mechanisms of change has been unsettling. Across the traditions are a number of conflicting ideas and what I will call *subtheories*, each of which pertain to a limited aspect of the dynamics within a group or the relationship of the individual to the group, and that purport to explain the measured outcomes. Popularly applied subtheories come from social psychology, such as social learning, social comparison theory, or social efficacy. Others were developed from studying professional group psychotherapy (e.g., Yalom’s [1970] curative factors), the sociology of deviant behavior (e.g., stigma; Goffman, 1963), or other domains. A few are specific to certain SHGs, such as the spirituality idea applying to AA and other 12-step groups (as was described above). The “helper” therapy principle (F. Riessman, 1965) is specific (but not exclusive) to SHGs, as is “experiential knowledge” (Borkman, 1976a).

In an extensive and thorough review of addictions recovery research on mechanisms of change, Kelly, Magill, and Stout (2009) at least organized the subtheories and theories into three classes: first, common therapeutic processes, such as self-efficacy, motivation to change, and active coping; second, AA-specific practices, such as acceptance of powerlessness, belief in a Higher Power, or commitment to AA; and third, social and spiritual processes. In the latter, “social support” refers to both general social support or to changes in health-promoting social networks, while spiritual practices mentioned were religiosity, meaning-seeking, hope (also a common process and one of Yalom’s curative factors), and internal locus of control (another common process). Note how overlapping they are!

The same concepts, such as “helping others,” are used quite differently by different researchers and connected to quite different subtheories. There is extensive lamenting about either the large number or the lack of theoretical explanations accounting for mechanisms of change or why benefits accrue or outcomes occur. Among the multitude of subtheories and theories regarding mechanisms of change, few have been empirically tested (Finn, Bishop, & Sparrow, 2009). How researchers use the same concepts in varying ways will be illustrated with two important examples: “helping others” and “social support.”

Consider five ways that “helping others” has been viewed in the research:

1. The “helper” therapy principle (F. Riessman, 1965) states that individuals who help others gain by helping—*Helping you helps me!* By 1990, F. Riessman stated that SHGs had restructured helping relationships with the concept that people are both givers and receivers of help, not just passive recipients of help. This concept has been applied across the spectrum of groups.
2. Helping others is a rewarding activity that contributes to the outcome of abstinence from substance abuse. Moos’s (2008, p. 398) theory of the “mechanisms of change” by which participating in AA or other SHG will produce desired outcomes involves four theoretical aspects: social control (consisting of support, goal direction, and structure), social learning (consisting of positive norms and role models), behavioral choice (consisting of involvement in protective activities such as social events, helping others, religion, or physical activity), and stress and coping theory (consisting of identifying stressors and building coping skills, self-esteem, and efficacy).
3. Helping others is part of AA’s spirituality (Zemore & Pagano, 2008, p. 141). As Zemore and Pagano put it, “helping others is viewed as a cause as well as an effect of personal recovery and spiritual transformation” (p. 142). They argue that helping may serve three functions: Helping contributes to the survival of AA as an organization; receiving help from others may strengthen bonds of social support in AA, which itself contributes to sobriety; and helping others may directly contribute to sobriety (as AA believes; Zemore & Pagano, 2008, pp. 142–143). This applies to AA and other 12-step programs.
4. Helping others can be categorized as recovery specific (helping maintain abstinence), general “life helping” (e.g., job hunting or child care), or “community helping” (e.g., volunteering to help in a homeless shelter or food bank; Zemore & Kaskutas, 2004); helping others can be measured by the amount of time spent on each form of helping (Borkman & Kaskutas, 2000).
5. In helping others, an individual becomes active, which is pivotal to SHG participation (Finn, Bishop, & Sparrow, 2009), as discussed in relation to GROW members who have mental health issues.

Thus, “helping others” is a central element in SHG participation, but it is viewed in many different ways.

A second example of a key feature of SHG is social support. Interestingly, it appears that the addictions recovery tradition often views the developing of sober networks as part of the dynamics of change, but not as outcomes, whereas the psychosocial tradition views the developing of social networks as the benefits of participation.

The concept of social support in these literatures rarely distinguishes between dysfunctional and positive support, partly because they are dealing with SHGs, which generally offer positive support. In contrast, Tracy et al. (2010) studied low-income women in a professional treatment program who were returning to their substance-using community. SHGs were not mentioned. They distinguished between negative and positive support as the social support literature does (e.g., Christakis & Fowler, 2009; Cohen & Syme, 1985; Vaux, 1988).

We turn now to the empirical research linking participation to mechanisms of change and to benefits in the psychosocial tradition. This subsection is based on several preexisting reviews of the literature, and it is neither thorough, systematic, nor complete. It is merely a sampling of reviews. First, two reviews—Kyrouz, Humphreys, and Loomis (2002) and the Self-Help Interest Group (2013)—cover general SHGs, such as groups for caregivers; for parents of children with cancer, disabilities, or other conditions; for widows; and for people with various chronic diseases; as well as for people with serious mental illness (SMI) and for addictions. Next, the Pistrang, Barker, and Humphreys (2008) review is limited to research on SHG participation for people with SMI.

All the reviews set minimum basic methodological criteria for including a research project. Kyrouz, Humphreys, and Loomis (2002) criteria were to include only those quantitative studies with a comparison group (e.g., comparing SHG participants to similar others who did not participate in a SHG) or longitudinal studies in which the same people are followed over some time period. Pistrang, Barker, and Humphreys (2008, p. 111) describe their review as using a treatment evaluation perspective, in which studies using the outcomes that a professionally led intervention would use were selected; they used the same criteria for inclusion as Kyrouz, Humphreys, and Loomis (2002). The Self-Help Interest Group (2013) used similar criteria but did not discuss them.

There are no claims of SHG participation extending life expectancy or reducing death rates. Research has not been interested, for the most part, in showing that SHG participation results in reducing symptoms of various chronic diseases, but rather that participation is linked with more social support, less psychological distress, better coping strategies, more well-being, and less shame and negative emotions. Often participation leads to increased empowerment and capacity to advocate for oneself within the health care system (Trojan, 1989), withdraw from abusive relationships, or set more protective boundaries (Sanders, 2009). A few examples will be given of specific studies, but the reader is invited to read the reviews for a wider range of examples.

* Unexpected findings are that participants in SHGs become more discerning and reliable patients and work more collaboratively with their professional treatment providers (Self-Help Interest Group, 2013);
* SHGs for people with chronic or psychiatric illnesses and their relatives and for people with disabilities “have an emancipating effect; they help to free members from burdens of disease, from passiveness, lack of knowledge, unsatisfactory relationships, and most important, from professional and bureaucratic domination” (Trojan, 1989, p. 229);
* SHGs help diminish the stigma attached to physical and mental health conditions by changing the attitudes of families, health workers, and support networks and by helping the affected people better cope with stigma (Self-Help Interest Group, 2013);
* In some cases, the impact is very specific to the condition. For example, in a group for parents who lost a child, those engaging in the SHG who developed friendships with members that met outside the group (i.e., developed social support) found that they became more comfortable talking about their loss to others, and they experienced less self-directed anger, whereas psychotherapy did not have these effects (Kyrouz, Humphreys, & Loomis, 2002, p. 78);
* Various studies show that those with SMI who participate in a SHG have reduced rates of hospitalization and shorter lengths of stay when hospitalized (Kyrouz, Humphreys, & Loomis, 2002; Self-Help Interest Group, 2013);
* Raiff (1984) compared Recovery, Inc. members, many of whom were ex-mental patients with SMI, with members of the general population, and found a strong association between length of time participating in Recovery, Inc. and its benefits (as other studies have shown); those who had participated for two or more years had as high or higher levels of life satisfaction than the general public.
* The Self-Help Interest Group (2013) concluded that, for those with SMI, various studies show SHGs’ benefits of tangible social support, peer validation, and valuable coping and interpersonal skill development, but also that SHGs can make an important difference between being disabled by mental illness or living with it productively.

Since social support is regarded as a critical mechanism of change or an outcome, does one’s outcomes improve if there are multiple reinforcing sources of social support? An unusual study examined the combined effects of Oxford House residency (e.g., clean and sober residents in recovery) and attendance and engagement with AA. Random assignment of individuals in treatment were made to either Oxford House or to usual care, and they were followed over a two-year period. Those highly involved in AA increased their odds of abstinence by 88 percent (Oxford House) versus 53 percent (usual care). Low attenders or non-attenders of AA over a two-year period had fairly similar odds of abstinence—31 percent for Oxford House and 21 percent for usual care (Groh et al., 2009).

The addictions recovery tradition has an extensive research base on AA effectiveness or outcomes and mechanisms of change, and a smaller literature on alternatives to AA such as Double Trouble in Recovery, Women for Sobriety (WFS), LifeRing, or SMART. Two reviews summarize findings on the outcomes of participation in AA (Kelly, Humphreys, & Ferri, 2020) and the mechanisms of change in AA (Kelly, Magill, & Stout, 2009). Both reviews are from the addictions recovery tradition and use positivistic criteria for inclusion in the review. The first review (Kelly, Humphreys, & Ferri, 2020), which is from the Cochrane Database of Systematic Reviews, is the most systematic and rigorous that I have ever seen.

The Cochrane review (Kelly, Humphreys, & Ferri, 2020) searched English-language and non-English-language literature very thoroughly for studies of peer-led AA groups and professionally delivered treatments that facilitate AA involvement (i.e., 12-step facilitation [TSF]). Among the outcomes included in the review were abstinence or reduced drinking, reduced alcohol-related consequences, alcohol addiction severity, and reduced health care costs. The review’s selection criteria permitted the inclusion of randomized controlled trials (RCTs), quasi-RCTs, or non-randomized interventions that compared AA or TSF (henceforth AA/TSF) with other interventions such as Project MATCH (Project MATCH Research Group, 1998). They excluded studies whose participants were coerced by court order or employer. They included a measure of the risk of several kinds of bias, including self-selection, attrition, and reporting bias, following Cochrane review procedures.

Twenty-seven studies that met their criteria, involving 10,565 participants in total, were reviewed. They summarized their key findings as follows: “Manualized AA/TSF interventions usually produced higher rates of continuous abstinence than the other established treatments investigated. Non-manualized AA/TSF performed as well as other established treatments” (Kelly, Humphreys, & Ferri, 2020, p. 3). In other words, the clinically delivered TSF interventions designed to increase AA participation usually lead to better outcomes of continuous abstinence. They elaborate: “This effect is achieved largely by fostering increased AA participation beyond the end of the TSF intervention. AA/TSF will probably produce substantial healthcare cost savings while simultaneously improving alcohol abstinence” (p. 3). These findings are somewhat confusing, but my understanding is that, scientifically, they could not measure AA participation directly; so, in order to conduct valid randomized controlled trials, they had to start with clinical settings, professional therapists, and captive patients who could be randomly assigned to different treatment conditions or “usual care.” The manualized treatments indicated that the clinicians were well trained in delivering a standardized message that educated patients about AA and intensively referred patients to AA. Patients were followed up with for periods of six months and one, two, and three years, and their attendance and engagement with AA ascertained at each time period along with their abstinence and other health measures. Since the clinical treatment lasted only a short time, but AA attendance could continue over the entire course of the study of up to three years, AA attendance and engagement became more important in understanding the abstinence outcome than the TSF, which in effect only got them to AA.

The 2020 Cochrane review finally provides substantial and scientifically valid evidence that AA through TSF is effective for keeping people with alcohol use disorders sober in the long run. The next question, then, given AA’s effectiveness, is what our knowledge is about the mechanisms of change that can explain it. Kelly, Magill, and Stout’s (2009) rigorous review of the empirical evidence stated that the common factor mechanisms, such as self-efficacy, motivation for abstinence, commitment to recovery, and behavioral coping, partly explained AA’s success. Evidence of the AA practice mechanisms was less conclusive, which may be due partly to methodological inconsistencies in conceptualizing and measuring them. Social and spiritual change measures were mixed. Both general social support as well as changes in health-promoting social networks were important mechanisms explaining abstinence, but the spiritual ones showed a mixed picture, partly due to conceptual and measurement challenges and inconsistencies. Kelly, Magill, and Stout’s (2009) conclusion, made in a different voice (as if they threw up their hands in exasperation) was: “AA’s effectiveness may not be due to its specific content or process. Rather, its chief strength may lie in its ability to provide free, long-term, easy access and exposure to recovery-related common therapeutic elements, the dose of which can be adaptively self-regulated according to perceived need” (p. 236).

Leonard Borman (1992) and George Vaillant (2014) have quite different reactions and suggest key ingredients that have been ignored by the scientific researchers. Leonard Borman (1992), speaking about SHGs in general, not just AA, summed up the mechanisms identified in the research—such as helping others, instant identity, social support, and the *meaning perspective*—as “based on a central underlying mechanism: love. Members of these groups share a selfless caring that is quite different from the impersonality that frequently occurs in our bureaucratic systems” (1992, p. xxv).

George Vaillant (2014), referring to AA, thinks they have “biological spirituality,” by which he means that AA meetings and relationships foster positive emotions of love, joy, hope, trust, compassion, forgiveness, and especially gratitude that are the “language of the heart,” and are based on the limbic system of the brain, not the rational modern scientific neocortex. “AA succeeds because it turns the limbic brain, hijacked by alcohol, to return to the purposes for which evolution designed it” (2014, p. 223). He explains how the 12 steps, relationships, and AA program relate to the “language of the heart” and connect with the limbic system of the brain. Vaillant, a psychiatrist, scientific researcher, and nonalcoholic AA trustee, followed alcoholic men over a forty-year period of research and has observed AA for decades. He says that for thirty-five years he has “marveled how alcoholics, by giving empathic comfort to others, and by focusing daily ‘on a power greater than themselves’ and upon the positive emotions in general, remain abstinent” (2014, p. 215). He thinks that AA discovered positive emotions fifty years before modern psychology did. He also says: “I believe that AA provides a concrete example of spirituality being made safe for human consumption” (p. 215). He argues that AA differs from cults, universities, or religions because it evolved from “biological spirituality, not superstitious religion or institutional greed” (p. 220).

We complete this section with a brief consideration of what is known about the downsides or limitations of self-help/mutual aid. I distinguish between two forms of criticism about SHGs. First are negative aspects and limitations internal to the SHGs and their movement—those aspects over which they have control. Inadequately cohesive groups, groups that damaged their members, inappropriate dependencies or exploitation of members, and exaggerated promises fall into this category. Second are distortions created by others outside the movement by people or professionals who co-opt and appropriate aspects of mutual aid, misuse it for cost-cutting reasons, and the like. The self-help/mutual aid movements have little if any control over dealing with outside forces that misuse it; other than merely noting this, I will not deal with this issue here.

Chesler (1990), concerned about the “dangers” of SHGs expressed by some professionals, did a small study as part of his larger research on SHGs for parents of children with cancer (Chesler & Chesney, 1995). He personally interviewed ninety-three professionals (physicians, social workers, nurses, and other health care workers who worked with the cancer SHGs and thus knew about them firsthand) asking if they had heard professionals discussing SHGs as dangerous, and if so, what were regarded as potential “dangers,” and if they had seen evidence of them. The problematic issues were either problems for the professionals, such as anti-professionalism, fear of losing clients, or challenges to the authority of professionals; or issues for the members and parents, such as spreading misinformation or having emotional conversations about their children that parents find disturbing. When asked about evidence of the occurrences of these problematic issues, fifty-seven interviewed professionals had heard of “dangers,” but only fifteen had any evidence of any of them. Chesler concluded that potential problems were more hypothetical than actual, and that they perhaps represented professionals’ fears of SHGs in themselves constituting a challenge to professional practice on a larger scale. Chesler recognizes that there are problematic issues, but evidence of them is rare.

Among the early researchers, Gartner and Riessman (1977) were among the most explicit about the potential limitations of self-help. There was concern that they could be misrepresented and used as inexpensive services substituting for needed specialized professional services (instances of this are discussed in Section 4). A major concern has been that self-help initiatives often maintain primary emphasis on the individual, thereby neglecting advocating for changes in the larger system that were contributing to the individual problem (Gartner & Riessman, 1977, p. 121). Another concern was that many self-help approaches had been directed largely to the middle-class groups, and that the poor and lower-class were often neglected (Gartner & Riessman, p. 123). These remain concerns among many critics. Later, by the 1990s, as SHGs were becoming institutionalized with the attending misuse, appropriation, and co-optation in some quarters, F. Riessman and Carroll (1995) became concerned anew about SHGs’ commodification; their becoming controlled by professionals who, reshaping SHGs on the professionals’ terms, renamed them “support groups”; and other misuses by outsiders. I have been personally bothered by unfair criticisms of SHGs that inappropriately equate some of their ideas with for-profit schemes or condemn them outright, or when SHGs’ *meaning perspectives* or impacts are misunderstood, oversimplified, exaggerated, as Rapping (1996) does in *The culture of recovery*.

Studies usually do not find any instances of a SHG damaging its participants, but the skeptic would question whether opportunities to express negative impacts were available in the way that data were collected. Trojan (1989), studying members from sixty-five SHGs in Germany, reported 1–4 percent negative comments among the participants, but failed to describe them. An interesting current example is found among dually diagnosed people who attend the 12-step group Double Trouble in Recovery: While they are qualified to attend AA, they sometimes feel unwelcome or uncomfortable in AA meetings because they are on psychiatric medications, which are regarded negatively in some AA groups (Laudet, 2008; Laudet et al., 2004).

Dependency on the group, if not outright using it as a crutch, had been an early charge leveled against AA and other addictions recovery groups that expect long-term membership. At the time, scientific addictions research had not yet studied the changes in the brain that make it a relapsing problem, whereas medical addictions research has now redefined it as a chronic relapsing disease, such that AA’s lifelong support is now seen as valuable (White, 2009). But SHG researchers changed their opinion about dependency on AA separate from the findings of medical science.

Researchers who, in the 1970s, criticized AA as encouraging dependency, evolved their way of thinking. Riessman, by the 1990s, devoted a chapter to “the special significance of the AA model,” citing its large impact on mainstream human services and “its comprehensiveness, including the theoretical structure for interpreting the phenomenon of alcoholism and its intervention rationale, broad infrastructure of help, and remarkable organizational model” (F. Riessman & Carroll, 1995, p. 53). By 1993, Katz, in his book *Self-help in America*, maintained that the most fundamental and important classifying distinction is between 12-step and non-12-step groups, with AA being the prototype of all 12-step groups (1993, p. 9). Vaillant (2014), who uses medical science information, made the distinction between healthy dependencies, such as on family, friends, regular exercise, or AA for alcoholics, and unhealthy ones such as smoking, inactivity, or gambling.

AA has maintained its distinctive organizational form (while becoming more inclusive toward gay and lesbian people, women, etc.), but researchers’ attitudes toward AA have changed quite dramatically. In the next subsection, we see how spinoffs and offshoots have changed the fundamentals of much in the SHG world while expanding mainstream human services to incorporate elements of self-help/mutual aid.

## 3.4 Outside the Rooms: Spinoffs and Offshoots

*Spinoffs* are self-help/mutual aid innovations that remain peer-run, also value lived experience, and have similar *meaning perspectives* to the original SHG, but may differ in goals, organizational forms, or leadership structures, and are not organizationally affiliated with the original SHG. For example, spun off from AA, Oxford Houses organize people in addictions recovery to rent and operate democratic, self-run, sober recovery houses following the values and principles of AA. A key difference is that the national-level Oxford House nonprofit organization tightly controls criteria and standards for local Oxford Houses in the communities (Jason, Ferrari, et al., 2006). Self-help groups and self-help organizations are often incubators of mutual aid innovations—partially because, as voluntary member-owned and member-run entities, their members learn through their participation how to create and run mutual aid collectives. The histories of many AA spinoffs, such as Gamblers Anonymous or Overeaters Anonymous, show that an AA member who has a second problem (such as gambling or overeating) was likely to be a founder. AA’s 12-step/12-tradition organizational framework has been analyzed to account for the frequent tendency of innovative initiatives to spin off similar but unaffiliated organizations, due to their operation of a self-organizing learning environment (Zohar & Borkman, 1997):

A self-organizing perspective offers many valuable ways of understanding decentralized, nonhierarchical forms of organization such as AA. The perspective can help articulate a radically different understanding of the nature and basis for organization in AA that is characterized by the emergence of novel patterns and configurations at both the organizational and group levels. It can help us understand how self-help organizations such as AA have flourished by building on the self-guided discovery by local groups of creative alternatives for carrying out an organization’s core values and vision. … It appears that the absence of highly structured, systematic rigidity and top-down, planned control evident in this case study can widen the spectrum of organizing options and set the stage for organizations to imaginatively seek new sources of vitality and self-renewal. (pp. 549–550)

*Offshoots*, on the other hand, are hybrid initiatives that combine self-help/mutual aid and professional elements, but are usually controlled by professionals in formal, often bureaucratic organizations. An early example is the Minnesota Model of addiction treatment, which was originally designed in the 1950s as drawing half from 12-step AA ideas and half from professional models, but over time evolved into professionally dominated organizations that utilize 12-step AA ideas as interpreted by professionals (White, 1998). A Fountain House clubhouse, for ex-mental patients and persons with severe mental illness, is a hybrid offshoot that started with mutual aid and professional elements, but evolved into an unusual structure: The board and leadership are held by professionals and business persons, but members maintain extensive control of their daily work (Doyle, Lanoil, & Dudek, 2013; Laratta & Borkman, 2012). Offshoots are frequently developed by professionals or entrepreneurs appropriating elements of self-help/mutual aid for professional services or as profit-making ventures in the marketplace, while often using names that confuse and blur the differences between the original self-help/mutual aid initiative and the appropriated ones.

This subsection calls attention to spinoffs and offshoots, which will be introduced but not extensively reviewed, since they are tangential to the review. There may be hundreds of innovative spinoffs and offshoots of SHGs and SHOs that have been created but are unrecognized because they have not been researched. Here we consider only those found in professional publications.

Since the spinoffs and offshoots from AA are so different from those of the mental health consumer/survivor movement, they will be discussed first. In between these discussions and acting as a transition is Case Illustration 9, pertaining to SHARE!, an innovative self-help center that was inspired by, and draws upon, all three movements, and is relentlessly changing and eclectic.

### 3.4.1 AA-Inspired Spinoffs and Offshoots

AA’s 12-step/12-tradition anonymous model has been copied up to ninety-five times, each directly changing only a few words to describe the type of addiction or condition of concern (White & Madara, 2002). Each 12-step SHG obtains permission from AA’s World Service Office in New York City to use the 12 steps and traditions as long as they remain organizationally unaffiliated. Laudet (2008) chronicles the history of the major addictions recovery groups, such as Narcotics Anonymous and Cocaine Anonymous, up to the more recent development of dual-focus groups for SMI and substance use disorders (SUDs), such as Double Trouble in Recovery. Many 12-step/12-tradition anonymous groups are listed in the national directory published by the Self-Help Clearinghouse of New Jersey (Broderick & Rodenbaugh, 2009).

Neurotics Anonymous, for mental illness issues, began in the 1950s but changed its name at some point to Emotions Anonymous. The only 12-step spinoff for SMIs, to my knowledge is GROW, which developed in Australia; GROW revised the 12 steps somewhat and modified the group format (Finn, Bishop, & Sparrow, 2009).

Another type of spinoff from AA was the more formal and complex organization. As AA grew and developed, especially in the 1950s and later, members around the United States and Canada extended themselves to other alcoholics by creating additional services to help them sustain sobriety and develop a productive life. Many of these efforts were never publicized; we assume they were gradually absorbed by professional services or withered away. In California, these social model recovery programs were more fully developed, articulated, and documented from the 1950s to the 1990s, although much of the documentation is in unpublished gray literature (Borkman, Kaskutas, et al., 1998). The Institute of Medicine (1990) identified California’s social model of recovery as the most prominent of the sociocultural model in formal treatment.

California social model recovery programs were staffed by recovering alcoholics in AA and provided an extensive range of alcohol (and later SUD) services from social setting detoxification units to recovery residences known as sober living houses, neighborhood recovery centers, and other services (Polcin & Borkman, 2008; Room, Kaskutas, & Piroth, 1998; Shaw & Borkman, 1990). *Social model recovery* referred to a specific form of service inspired by AA’s philosophy and practices; the term “social models” has been used by others in a generic sense to denote nonmedical interventions.

Sober living houses are residences for people, especially in early recovery, that are financially self-sustained through resident fees and usually do not accept insurance or public funding; they are not licensed or monitored by the state, as they do not provide formal treatment. Consequently, they are free of regulations like limits to lengths of stays, and residents can usually stay as long as they want, which could be years in a few cases (Polcin & Borkman, 2008, p. 99). Today, sober living houses span a continuum of adherence to AA philosophy and practices, while the sober living coalitions that maintained coherence and fidelity to the standards among sober living houses—when the cofounders of sober living coalitions were active—are gone (Polcin & Borkman, 2008, p. 99). The California social model recovery services were overtaken by the forces of medicalization and professionalization of alcohol treatment services along with the practices and financing accompanying managed care in the 1980s and 1990s, and withered away except for sober living homes (Borkman, Kaskutas, & Owens, 2007).

Turning now to offshoots of AA, we read about 12-step facilitation (TSF) in the discussion of outcomes. TSF is based on the 12-step-based professional treatment (a generic name) that was originally called the “Minnesota Model” or “Hazelden Model” (Slaymaker & Sheehan, 2008). The Minnesota/Hazelden Model was developed in Minnesota in the early 1950s, combining AA’s philosophy, 12 steps, and practices with then-evolving professional treatment. Within the professional treatment context of the Minnesota/Hazelden Model, the 12 steps form the foundation for the provision of care along with cognitive–behavioral and other professional strategies. Important components of the model were the following: Use a multidisciplinary team of professionals; include recovering people on the team; promote the need for and value of an aftercare program; respect, understanding, and acceptance of the dignity of each patient; the belief that time away and association with fellow alcoholics was central to recovery (McElrath, 1997).

The Minnesota/Hazelden Model spread around the country in the 1960s and later, and then around the world. It became the most common treatment program for SUDs in the United States (Institute of Medicine, 1990). Subsequently, Project Match (Babor & Del Boca, 2003), the first large-scale randomized, multisite study to compare the effectiveness of different treatments, developed the main components of the Minnesota/Hazelden Model into a manualized format that became TSF. As described in Subsection 3.3.2, AA/TSF was found to be more effective than cognitive–behavioral therapy or motivational enhancement therapy over a three-year period because it increased continued AA involvement, which led to higher rates of abstinence.

With the success of TSF in Project Match, other forms of professional treatment with intensive referrals to AA were developed. Kaskustas, Subbaraman, et al. (2009) developed MAAEZ (Making AA Easier), which differed from TSF in its use of recovering counselors who had personal experience with AA to teach it, and MAAEZ helped clients interact with people they would meet in AA or NA. Interestingly, MAAEZ was especially effective at producing higher abstinence rates among people with severe psychiatric illness, people previously exposed to AA, and agnostics and atheists.

Finally, of the AA offshoots, we discuss Synanon and “therapeutic communities,” both for drug addicts. Synanon, established by Chuck Dederich in 1956, began as an SHG for drug addicts. Dederich was a sober alcoholic who left AA to start his alternative residential mutual aid community for people with drug addictions. Researchers were enthusiastic about Synanon in its early days in the 1970s (Yablonsky, 1965). Later, Synanon was dropped from researchers’ lists of SHGs when it changed into a destructive cult. Jantzen (2001, Chap. 13) details the multiple reasons for the large changes over the years: The charismatic Chuck Dederich resumed drinking alcohol; he had bipolar disorder with unpredictable destructive behaviors; the IRS refused to renew Synanon’s tax-exempt status; the community eroded into corruption, permitting abusive behaviors and eventually disbanding in 1991 (Jantzen, 2001, p. 215). Some of its ideals, vision, and practices, such as “The Game,” were incorporated into a new hybrid client- and professionally run drug treatment program known as “therapeutic communities” (TCs; De Leon, 2000; Kennard, 2004) which continue to this day.

Case Illustration 9 is of SHARE! (the Self-Help And Recovery Exchange) in Los Angeles, an innovative mental health consumer-run organization (CRO) that is grounded in the self-help and mutual aid ethos of SHGs and eclectically and effectively adopts practices from all three self-help/mutual aid movements.

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Case Illustration 9

Formalized SHARE! Attenuates and Inverts Hierarchy to Cultivate Mutual Helping

As previously discussed in Section 2, the self-help small-group structure is especially conducive to mutual helping and peer support. In contrast, a formalized nonprofit organization, with its hierarchy of board, officers, staff, and members, minimizes and even threatens opportunities for peer support and mutual helping. Most mental health CROs (consumer-run organizations) in the United States are formalized nonprofit organizations—a requirement of their government funding—and grew out of the advocacy, not mutual aid, orientation of the mental health consumer/survivor movement. Accordingly, mental health CROs are susceptible to limited mutual helping and peer support, a problem noted in the literature without a solution (Myrick & del Vecchio, 2016; Salzer, 2010).

One CRO that recognizes the dilemma and has taken steps to counteract it is SHARE! (the Self-Help and Recovery Exchange; http://shareselfhelp.org) in Los Angeles, California, which has developed strategies to maintain mutual-helping relationships within a formalized nonprofit organization. SHARE!, an innovative and complex twenty-seven-year old self-help and mutual aid center, grew out of the ethos of the three movements.

SHARE! has three strategies to attenuate the hierarchy and further egalitarian relationships: (1) a *meaning perspective* that encompasses a consistent value system and ethos of self-help/mutual aid and recovery and an open, research-based learning environment; (2) staff are required to be currently successful in active recovery from addiction, mental illness, or other conditions, and thus serve as recovery role models; (3) an innovative interaction system of principles and techniques, referred to as the “Toolkit,” that cultivates respectful, personal, and supportive relationships that are egalitarian and enhance mutual helping and recovery. As SHARE! management likes to say, “There are two things to do when someone comes to SHARE!—help someone else or go to a meeting.”

This case study of SHARE! is based on six week-long visits that took place in 2008, 2009, 2010, 2014, 2016, and 2019, using mixed methods of interviews, participant observation, and archival materials (Borkman, 2010a, 2011b; L. D. Brown, Tang, & Hollman, 2014; Hollman, 2011, 2013, 2015). Permission to conduct the research was given by the SHARE! board of directors. A majority of SHARE’s board of directors and management triumvirate are mental health or addictions consumer/survivors, which is an important criterion for the definition of a mental health CRO. The management triumvirate makes collective decisions with extensive input from staff and participants. Advocacy with the local county funding agency to ensure the rights of SHARE! participants and others with behavioral health issues, and to maintain or increase the integrity and funding of consumer-run initiatives, is accomplished by having top management participate in key county committees.

Participatory action research methodology (Nelson et al., 2010), in which the researcher involves the participants in the research process, has explicitly been used in this research in that SHARE!’s management have been actively engaged with the research design and facilitated the fieldwork. The fieldwork included attending board, management, and staff meetings; staying for a week in collaborative housing; and participating for a weekend in the peer respite program. I observed and interviewed staff, management, and board members and collected documents and data during each visit.

I periodically give the management triumvirate feedback on my findings and analyses. They reviewed my draft documents about SHARE! for factual and meaning accuracy, although the analyses and conclusions are mine. SHARE! also presented me with the Frances E. Jemmott Award for self-help research in 2009. Ruth Hollman (SHARE!’s executive director) and I have also presented about SHARE! at professional conferences (Borkman, 2011b; Hollman, 2011, 2013).

SHARE! began as an all-volunteer collective of ten to twenty-five peers spearheaded by Ruth Hollman and Elizabeth Hartigan, two of the current management triumvirate (Hollman, 2011; SHARE!, *c*. 2010a), who were dissatisfied with the operation of self-help groups in Los Angeles in the early 1990s. From the beginning they were devoted to respectful and egalitarian personal relationships, hosting self-help group meetings as the key to recovery, encouraging mutual support, and, most radically, never kicking anyone out of SHARE!. Under the auspices of a California 501(c)(3) nonprofit organization, they formed a board and working committees in 1991 and opened SHARE!’s first center in Venice, Los Angeles, in December 1992 as a safe, affordable meeting space for self-help groups. SHARE! described itself as a “safe, loving environment for people to get help—not by being told what to do by an expert, but by developing their own solutions” (SHARE!, *c*. 2010a). In 1994 they moved into nicer quarters in nearby Mar Vista, and finally to their current location in Culver City, all contiguous suburbs of Los Angeles. The first grants they received, in 1996 and later, were from California-based foundations, which allowed them to hire paid staff for the first time. Los Angeles County, which has 13 million residents and is larger in size and budget than most states, provides most of SHARE!’s major funding today through the Los Angeles Department of Mental Health. Some funding also comes from donations, special events, and grants for special programs.

In 2009, SHARE! opened a second self-help center with five meeting rooms for SHGs in downtown Los Angeles, positioned deliberately between the upscale business district and Skid Row—an area of homeless people. In 2014 the two self-help centers together hosted more than 130 weekly self-help group meetings, with over 5,000 attendees monthly (SHARE!, 2015).

SHARE! continues to grow. For example, in 1993, a volunteer staff operated on an organizational budget of less than $18,000, which grew to a paid staff of ten with a $305,600 budget in 2003. By 2018, thirty full-time paid staff operated five major programs on a budget of $2,871,000 (R. Hollman, personal communication, February 15, 2019). SHARE! has become a multiservice agency “focused particularly on addressing the needs of people who fall through the cracks elsewhere” (SHARE!, 2015) that offers a self-help clearinghouse with updated information about and referrals to SHGs throughout Los Angeles County; collaborative, affordable rental housing for homeless disabled persons within single-family homes, in partnership with private landowners (launched in 2005); a volunteer-to-job program that trains participants to develop skills and confidence for competitive jobs; and, since 2013, a recovery peer-run respite residence, which is a homey, two-week residential program for people with serious mental health problems to become motivated to recover and develop skills for reaching their goals. SHARE! is unusually open to conducting research (e.g., see L. D. Brown, Hollman, & Tang, 2014), inviting investigators to use SHARE! as a research site and basing their programs on evidence-based practices.

Organizational Values: Mutual Help, Recovery, and Community

Although, organizationally, SHARE! resembles a CRO, it has maintained its SHG roots; it focuses on respectful, nonhierarchical personal relationships and emphasizes mutual support by creating opportunities for all participants to help one another. These values are primarily expressed in SHARE!’s mission statements (2010c, 2015), foundational concepts, and the content and principles of an innovative interaction system known formally as SHARE!’s “Peer Toolkit.” Foundational concepts include the following: “community is the goal and the method,” respect for diversity, nonviolent and noncoercive communication, respectful and egalitarian relationships, maximizing choices that participants have in their recovery, and “radical inclusion”—the idea that no one has or will be kicked out of SHARE! (unlike many mental health agencies that suspend or bar disruptive clients).

In contrast to SHARE!, the criterion for hiring peer provider staff in many CROs is simply that the person has received or is receiving mental health services of some kind (Clay, 2005; Solomon, 2004). Case studies show that this leads to situations where management and staff may know nothing about the mutual-help ethos and may even be extremely hierarchical or dictatorial (Borkman, Karlsson, et al., 2005; McLean, 1995). SHARE! developed a more nuanced understanding of requirements for effective peer staff that ensure that staff are knowledgeable about and committed to the mutual-help ethos through their experiences over the years. Staff are hired who are successful in current recovery—which means continuing to attend SHG meetings and working on personal issues. The requirement that staff be in active recovery is monitored at SHARE! in a low-key and useful manner. At the beginning of staff meetings, staff describe in general what self-help group meetings they attended in the last period of time, what personal issues they are working on, and what plans and actions they are taking to resolve the problematic issues (Borkman, 2010a). Further, they are trained in the concepts of and application of the Toolkit, the innovative interaction system.

The principles and techniques of this distinctive interaction system are referred to as “Tools of the Trade” (SHARE!, 2010b), and were devised and copyrighted by Ruth Hollman. As the Tools are used, they are reviewed and revised. By the 2019 field visit, the Tools had undergone a major overhaul and been renamed the SHARE! Peer Toolkit. The complex Toolkit training encompasses a wide variety of techniques borrowed from several 12-step groups and other SHGs, such as AA, Debtors Anonymous, Adult Children of Alcoholics, and Recovery International, and a sister program called Intentional Peer Support (Mead, 2008). Intentional Peer Support, used, among other places, in the state of Maine’s training program to certify peer support specialists (Hansen, Winton, & Mead, 2015), is also an interaction system designed to change peer providers from a helping role to peers learning together.

The present analysis of the 2010 Tools of the Trade was redone based on the 2019 field work, which included my spending a day in the training class and reviewing the SHARE! *Peer Toolkit Training Manual* (SHARE!, 2018). I categorized the twenty-nine Tools according to five functions germane to this article. The first function is to create a respectful, personal, peer relationship of unconditional regard that enhances a person’s dignity. The second function is to communicate in nonviolent and noncoercive ways—in other words, to avoid belittling or shaming anyone verbally. The third function designates staff to minimize the authority associated with their position. The fourth function is to be a positive role model to encourage constructive recovery. The fifth function is to deal with disruptive participants and resolve conflict in a manner that strengthens relationships among the parties.

Each of the five functions will be briefly described in terms of the Tools associated with it. The twenty-nine Tools are generic and their wording is informal, and any individual tool serves multiple functions. Over a third of the Tools (*n* = 10) fulfill the first function—to create a respectful, personal, peer relationship of unconditional regard and support that enhances a person’s dignity—and they are the following: “Triple A—attention, affection, approval”; “Include the person, exclude the behavior”; “Disclose one’s own lived experience”; “Socialize”; “Minimize your authority”; “Invest in the relationship over the long run”; “Find ways to agree with the person”; “Save the person’s face”; “Communicate we are on the same team”; and “Acknowledge and validate the person’s viewpoint.” These ten techniques cross-cut other relationships and seem to be at the heart of SHARE! relationships.

The second function is nonviolent and noncoercive communication. As one Tool describes it, “We are not the police, the judge, or God.” The techniques are intended to avoid belittling, shaming, or putting down the recipient of your communication, and they are “Disclosing—use I statements to share personal experiences”; “It’s my responsibility to communicate”; “Deliver same message in varying ways”; “No buts—‘and’ implies working together and ‘but’ implies isolation”; “Communicate suggestions indirectly”; “Build a relationship so behavior can be influenced”; “Presume innocence—avoid assumptions, stereotyping, scapegoating”; and “Accept people’s reality as valid for them.”

The third function designated staff to minimize the authority associated with their organizational position in order to reduce the social distance between themselves and peers. Four Tools seem to be expressly important for this function: “Disclosing your own lived experience in recovery”; “Socialize”; “Minimize your authority”; and “Helper-Therapy principle—let them help you.”

The fourth function is to be a positive role model to encourage constructive recovery. Seven Tools seem especially important: “Disclose one’s own lived experience”; “Socialize”; “Helper-Therapy principle—let others help you”; “Discover the person’s goals and help them pursue them”; “Acknowledge and validate the person’s viewpoint”; “Make a gratitude list for the person to focus on positives, not setbacks”; and “Point out the person’s recovery.”

The final function deals with disruptive participants and conflict resolution. Importantly, SHARE’s radical inclusion policy is possible because of the Tools covered by this function. Almost half (*n* = 13) of the Tools seem to be specially designed to handle disruptive participants or to resolve conflict: “Disclose one’s own personal discomfort with disruptive behavior”; “Save the person’s face”; “Include the person, exclude the behavior”; “Communicate all on same team”; “Find ways to agree with the person”; “Accept people’s reality as valid for them”; “The boundary is over there” (agree with a person criticizing an institution by saying it is the institution’s rules at fault); “Change the channel—do something surprising or different to distract someone”; and “Humor—laugh *with*, not *at* the person.” Another tool, “The corner sweep,” is a technique to prevent power struggles between two people: Two staff members approach the arguing pair and separate them, and each staff person separately validates a participant’s viewpoint. Also addressing this final function are the tools “Get ahead of the crisis—Look for triggers, take action and support people before things develop into a crisis”; “Normalize—Maintain the environment as it is intended to be”; and “Change plans—Use when there’s a pattern of behavior that is consistently producing undesirable results. Ask the person who needs to change or needs advice for what to do when this comes up.”

The innovative Toolkit creates a very high standard of behavior in always expecting. respectful, nonjudgmental, and personal peer relationships. These may be aspirational to some staff with limited years of recovery. Senior management and staff with long-term recovery may be more likely to attain these high standards; instances where senior management have been asked by newer staff to handle a disruptive participant occur in the field notes (Borkman, 2019). The extent to which staff consistently or effectively use them has not been systematically studied. However, the Toolkit has been indirectly validated by an external agency—for the last three years, the State of California has awarded contracts to SHARE! to train peers around the state to use the Toolkit. It will be interesting to see to what extent and where the Toolkit is disseminated and used by other SHOs and CROs over time.

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### 3.4.2 Spinoffs and Offshoots of the Mental Health Consumer/Survivor Movement

Since the mental health consumer/survivor movement was so advocacy oriented, politicized, and focused on working cooperatively with professionals to change the system from within (as suggested by their historical development described in Section 2), many of them abandoned SHGs and the initial mutual aid sharing circle. No noticeable spinoffs from their original SHGs exist, to my knowledge. Their legacy is with offshoots, namely peer support and government-funded, registered nonprofit 501(c)(3) organizations, which are circumscribed in their advocacy activities in order to maintain their tax-exempt status. Thus, the consumer/survivor movement has gained service agencies, but it has become prevented from carrying out extensive advocacy activities that could help change the mental health system from within, which was its primary goal. Individual recovery has become a secondary goal since the 1990s. Further, the movement has gained “peer support,” which increasingly means a job position in an agency (either CRO or mainstream mental health agency), such as that of peer support specialist, and it means training and certification as a specialist.

My decision to regard the successes of the mental health movement, the CROs, as offshoots of their original SHGs may be controversial, but in studying a number of them (see Borkman, 2014; Borkman, Karlsson, et al., 2005), especially SHARE! (described in Case Illustration 9), I have come to the conclusion that most CROs lack the conditions for mutual aid. In contrast, SHARE!’s management are very aware, if implicitly, that their formal organizational environment precludes automatic opportunities for participants to help each other (i.e., mutual aid) except in SHG meetings, and therefore that the staff and culture need to compensate and engender or recreate some of the conditions for mutual aid. They are doing this with their unusual interaction system, ethos, and staff recruitment and training. But other CROs are not doing this.

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

Carol Munn-Giddings and Melanie Boyce

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.

Insert Table 6 about here

## 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 lovingly.

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Table 1

Professional Versus Self-Helper Models of Helping, as Mediated by Organizational Context

|  |  |  |  |
| --- | --- | --- | --- |
| Dimension | Subdimension | Professional in agency | Self-helper in SHG or SHO |
| Background | Helper position | Professional job/career, livelihood | Person with troublesome issue needs resolving and support |
| Qualifications for position | Education, degrees, credentials, job experience | Similar lived experience of focal issue as peer; voluntarily participating in group |
| Helper’s stake in situation | Keep job; follow agency requirements; advance career; help client | Living/dying or quality of life; e.g., stigmatized or respected? isolated or supported? pain/disability or not? |
| Structure of relationship | Power | Hierarchical: client is subordinate | Self-helpers are egalitarian; seasoned self-helpers have more influence |
| Basis of relationship | Paid by agency via contract | “gift” relationship or personal commitment; nearly cost-free |
| Source of knowledge | Professional–scientific | Personal lived experience;group’s *meaning perspective* |
| Control of knowledge | Professional controls knowledge | Self-helpers own their experience; group’s *meaning perspective* is shared freely |
| How knowledge is expressed | Logico-scientific; jargon, technical terms | Everyday conversation; narratives/stories of lived experience |
| Role boundaries | Descriptor of helpee | “Patient” or “client” | “Self-helper” |
| Boundaries | Professional distance and objectivity; separation of roles | Helper and helpee roles are mutual and reciprocal; emphasis on personal involvement and relational connection |
| Extent of relationship | Restricted to helping | Multiple, depends on individual choice: e.g., peer, friend, mentor, acquaintance |
| View of focal issue | Extensiveness | Specific, technical, diagnoses, institutional | Holistic, thorough, includes existential (“why me?” questioning) or spiritual/religious dimension |
| When and amount of help available | Limited and scheduled; agency requirements | Community-based; meetings; varies but can be available 24/7/365; extensive |

Table 2

Number of Active Self-Help Organizations (SHOs) in the United States by Decade

|  |  |
| --- | --- |
| Decade(represented by selected year) | Number of active SHOs |
| 1955 | 30 |
| 1965 | 50 |
| 1975 | 116 |
| 1985 | 323 |
| 1995 | 359 |
| 2000 | 296 |

*Note*: Adapted from Archibald (2007, p. 67).

Table 3

Numbers of Mental Health Self-Help Groups, Advocacy Organizations, and Consumer-Run Services in the United States (by National Survey), 2002

|  |  |  |  |
| --- | --- | --- | --- |
| Type of organization | % of total organizations | # of organizations nationwide (estimate) | # of persons served nationwide (estimate) |
| Self-help group | 44% | 3,315 | 41,363 attend meetings |
| Advocacy organization | 40% | 3,019 | 1,005,400 belong to an organization |
| Consumer-run services/businesses | 15% | 1,133 | 534,551 members served |
| Total: | 99% | 7,467 |  |

*Note*. Adapted from “National Estimates for Mental Health Mutual Support Groups, Self-Help Organizations, and Consumer-Operated Services,” in Goldstrom, et al. (2006). Copyright 2005, Springer Science+Business Media, Inc.

Table 4

Characteristics of AA, the General Self-Help/Mutual Aid Movement, and Mental Health Consumer/Survivors as Social Movements

|  |  |  |  |
| --- | --- | --- | --- |
| Area of characteristic difference | Alcoholics Anonymous | General self-help/mutual aid movement | Mental health consumer/survivor movement |
| Type of social movement | “Partial social movement” (Bloomfield, 1994) | Health social movement (Archibald, 2007) | Classic social movement (Emerick, 1996) |
| Societal attitude when movement was founded | Alcoholism moral failing—1930s; jail drunks; health care ignores them | Medical sovereignty—1950s; patients comply; chronic diseases require patient participation | Serious, lifelong mental illness without recovery—1950s; ex-mental patients sent to communities without resources |
| Goals of movement | Personal recovery only; no social change goals | Groups varied: Some groups emphasized personal coping, others emphasized social change, some both | First priority was social change; second priority were personal coping goals |
| Political advocacy | None | Groups varied: Engaged in advocacy if they had social change goals | Majority advocated to change mental health system |
| Disagreements about social change | Not applicable | Groups varied | Radicals and moderates clashed about working within system or not |
| Developed system of beliefs and strategy? | Not applicable | No: Most SHGs and SHOs focus on focal issue in silo, not within larger self-help movement | Yes: Successfully advocated for government-funded but formalized CROs |
| Developed national coordinated advocacy organization? | Not applicable | Groups varied: Within their silos, some conditions developed national advocacy organizations | Yes: National coalition of statewide advocacy organizations |

Table 5

Borkman’s International Odyssey of Self-Help/Mutual Aid

|  |  |  |  |
| --- | --- | --- | --- |
| Year | Event, place | Insight gained or lesson learned | Where it is discussed in this literature review (in parentheses: associated publications) |
| 1992 | International conference, Canada | Great variety of mutual aid internationally | Section 2.2 (Lavoie, Borkman, & Gidron, 1994) |
| 1994 | Addictions Recovery Conference, Canada | Diversity in unity in AA; alternative addiction mutual aid in countries | Section 3.1 (Eisenbach-Stangl & Rosenqvist, 1998) |
| 1994 | Personal visit to Von Appen, former East Germany | When lifelong welfare provided, citizens do not learn to engage in voluntary action or SHGs | Section 3.1 (Von Appen, 1994) |
| 1995 | Field work for 5 months in Toronto, Canada | Subtle differences between SHGs in collectivistic Canada versus individualistic United States | Case Illustration 5 (Borkman, 1996a, 1996b) |
| 1997 | Research consultant, North Ireland | Observe new hybrid SHG with professional and mutual aid features | Section 3.4 (Sproule, O’Halloran, & Borkman, 1999) |
| 2000 | Visiting Professor at School of Nursing, Taipei, Taiwan | Invisibility of support groups and SHGs within the health care system | Section 3.1 |
| 2000 | Public presentation to SHG leaders and citizens, Yokohama, Japan | Laws and customs of civil society constrain SHG’s capacity to have up-to-date leaders | Section 3.1 (Oka, 1994, 2013b) |
| 2002  | Field work at mental health CROs in England | Terminological differences; greater citizen involvement in research in the United Kingdom | Section 3.4 (Borkman, Karlsson, et al., 2005) |
| 2004 | Research consultant, Sweden | Adapting US Fountain House clubhouse model; limited by labor laws | Section 3.4 (Karlsson, 2013) |
| 2008  | ISTR conference | Japanese researcher reveals huge differences from the United States | Section 3.2 (Borkman & Oka, 2005) |
| 2009–2014 | Guest Editor and Editor, *International Journal of Self-Help & Self-Care* | Little research done on SHGs and mutual aid since 20th century; most research is on peer support | Section 1 |
| 2012 | Field work in Croatia | Complexity of professional–SHG relationships in different civil societies | Section 4 (Borkman, 2015; Dill & Coury, 2008) |
| 2013–2016 | Writing handbook with international cast | Paucity of research using volunteering framework | Section 5 (Munn-Giddings et al., 2016) |
| 2020 | Working with Munn-Giddings to write encyclopedia article | Peer support researchers are disconnected from mutual aid research | Section 1 (Borkman & Munn-Giddings, 2020) |

Table 6

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

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| 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.

1. The reader may recognize a similarity between the research traditions discussed in Section 1 and the three social movements. The AA 12-step/12-tradition addiction social movement corresponds to the North American addictions recovery research tradition; the other two social movements are part of the North American psychosocial tradition. [↑](#footnote-ref-1)
2. White implicitly separates the AA recovery period from the professional/scientific period of modern alcoholism into two distinct entities, while Bloomfield (1994) explicitly separates them. [↑](#footnote-ref-2)
3. I witnessed this firsthand while on leave as a professor to be a visiting researcher at the NIAAA; I was asked to study a noncompliant alcohol recovery program in Los Angeles and a second one in San Diego, California, which resulted in my writing a monograph about two spinoffs of AA that were social model alcohol recovery programs common in California at the time. Upon reviewing the monograph, my NIAAA boss was not pleased with its positive view of nonprofessional programs and said explicitly to me that she would only see it published because I needed a publication for my résumé. [↑](#footnote-ref-3)
4. Borman had hosted a “Workshop on Explorations in Self-Help and Mutual Aid” in Chicago in 1974 comprised of researchers, leaders and members of self-help groups and medical personnel. This workshop was described in a 1975 report of the proceedings; Borman, 1975a. Borman also edited with Morton Lieberman the 1976 special issue on self-help groups in the *Journal of Applied Behavioral Science* and a 1979 book, *Self-help groups for coping with crisis*; Lieberman & Borman (1976b, 1979). [↑](#footnote-ref-4)
5. Note that this quotation credits SHGs with developing the recovery paradigm for the movement. [↑](#footnote-ref-5)
6. More generally, studies repeatedly find that SHGs who critique professionals and their therapies are also more likely to use professional services than people who do not go to SHGs (L. F. Kurtz, 1997; Wister, 1995). [↑](#footnote-ref-6)
7. A reviewer asked where I was in the listing of research resource center networks. Until the 1990s, I was an independent lone researcher who was invited to participate in sessions about SHGs at professional conferences and contribute to edited books (Borkman, 1976b, 1984, 1990b). I was on the planning committee of the Surgeon General’s Workshop on Self-Help and Public Health and worked with colleagues in professional associations. I knew major players from each of the first six networks except Richard Wollert and the team in Oregon. Note that most of the leaders of the first six teams were male. In the 1990s, I developed a very loose international network of colleagues from Europe (Munn-Giddings & Borkman, 2005; Borkman, Karlsson, et al., 2005) and Japan (Oka & Borkman, 2005, 2011) with whom I engaged in collaborative research. [↑](#footnote-ref-7)
8. I also wrote then that they were quite revolutionary but was unable to articulate in what manner. [↑](#footnote-ref-8)
9. As a guest editor, then editor, of the *International Journal of Self-Help & Self-Care* between 2006 and 2014, I witnessed firsthand the trend toward fewer and fewer articles on SHGs. Very few articles about self-help/mutual aid were sent to the journal, and I had to work hard to find suitable material for the issues; the available research was increasingly about spinoffs or offshoots or hybrids of self-help/mutual aid. [↑](#footnote-ref-9)
10. A specialty area I studied, taught, and worked in, medical sociology is a subspecialty in sociology that studies physicians as a specialized kind of occupation that is marked by its status and organization as a profession and the professional’s relationship with patients, other health care providers, and their organizations, among other issues surrounding health care. [↑](#footnote-ref-10)
11. The third sector has also been known by other names, such as the “independent sector,” “charitable organizations,” the “social sector,” and recently as “social purpose organizations” (W. W. Powell, 2020, p. 3); Habermas (see Chaudhary, Avis, & Munn-Giddings, 2013) also referred to it as the “public sphere.” [↑](#footnote-ref-11)