

**SOCIAL PHILOSOPHY AND FUNDING IN
SELF HELP: A UK-US COMPARISON**

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ABSTRACT

The consumer/survivor/service-user protest movements of the 1970s-1990s led to policy changes and government funding of mental health consumer-run or self-help organizations (SHOs). A cross-national study in the United States and United Kingdom-England of SHOs incorporated nonprofit organizations run by and for people with problems in common, considers the tightrope of accepting government funding which brings stability and legitimacy but also potentially conflicts with self-help/mutual aid ethos and practices. Case studies of two SHOs in England and three SHOs in the United States show that the self-help/mutual aid ethos is embedded in the organizations' practices. Complex and nuanced relationships between SHOs and sympathetic professionals facilitate these developments.

Historically, reforms of mental health services have been spearheaded by philanthropists and professionals, but the participation of people with mental health

problems (the recipients of service) was absent. Today, in many industrialized countries, mental health service users, ex-patients, and self-described survivors of psychiatric services are not only major advocates for change but are also providers of services. Organizations run by and for people with mental health problems are called Consumer Run Organizations (United States) and Service User Run Organizations (United Kingdom); but, we use the term Self-Help Organization (SHO) which we define as *Organizations run for and by people who share the same health or social condition for which they are funded to provide services.*

For the most part, we will be using the term “service user” rather than “consumer” because the latter has negative connotations for many in countries outside the United States. We report our findings from a cross-national study of mental health SHOs in the United States and United Kingdom-England.

The consumer/survivor/service user protest movements of the 1970s-1990s were inspired by philosophies of self-help/mutual aid and civil rights for persons with mental health problem (Campbell, 1987; Chamberlin, 1978, 1990; Riessman & Carroll, 1995). These social movements contributed to changes in mental health policy which were accompanied by government support and funding. This could be viewed as a great success story: however, research on the third sector or nonprofit organizations and voluntary action consistently shows that government funding of innovative service user based services is a two-edged sword (Milofsky, 1988; Salamon, 2002; Smith & Lipsky, 1993). Funding can provide stability and credibility, but values such as self-help peer-based philosophy and activities are antithetical to the bureaucratic and professionalized models on which most government services are based. Mental health service-user protesters (Chamberlin, 1978, 1990; Everett, 1994) and researchers (Felton, 2005; McLean, 1995) have similarly recognized the potential dangers that joining with mainstream services may bring. Government funding can threaten to co-opt, dilute the value, and compromise the philosophy and practice of service user run services.

In this article we are adding to the existing literature by illuminating the ways in which SHOs’ origins, philosophy, and practices still preserve the self-help ethos of the service user movements in the United States and the United Kingdom. While recognizing the dangers that inappropriate funding may have on SHOs, our study suggests that SHOs’ relationships with mainstream service providers and funders may be more complex and nuanced than it is portrayed in existing literature.

SOCIETAL CONTEXT

In England, mental health policy since the mid-1980s has evolved a mandate that users of services be involved in planning, providing, and evaluating services. The national health care system has a unified national policy that

obtains at all levels—local, regional, and national; consequently, professionals and governmental bodies assist service-users to develop forums and request representatives from grassroots self-help groups to governmental bodies deliberating on policy issues. Research has focused on the policy-oriented role of service users in governmental bodies rather than on self-help/mutual aid groups or organizations (Munn-Giddings, 2003). No accurate statistics of mental health SHOs are currently available in the United Kingdom.

The United States has no national health care system but a complex “non-system” of government and private health insurances; mental health policy is fragmented. The federal government can lead with new initiatives, pilot and demonstration projects, but the States who fund much of the mental health services have independent policies. The U.S. President’s New Freedom Commission on Mental Health Report (2003) recommended the inclusion of mental health “consumers” of service in policy deliberations of the mainstream system. The role of self-help and advocacy groups of mental health service users or their families has been significant. A September 2002 national survey of self-help groups, organizations, and services controlled by consumers identified an estimated 7,467 groups, organizations, and services run by and for mental health service users or their families in comparison with 4,546 traditional mental health organizations in the United States (Goldstrom, Campbell, Rogers, Lambert, Blacklow, Henderson, et al., 2006).

Self-help/mutual aid often starts in informally organized groups (SHGs) of egalitarian peers whose organizational structure must change when they receive funds to provide services; they must become legally constituted organizations with the hierarchy of a board and director who supervises staff, whether volunteer or paid. The SHO’s authority is the experiential knowledge of the service users (Schubert & Borkman, 1991). Self-help organizations (SHOs) are the equivalent of stand-alone consumer-operated service programs (COPs) run by and for service-users that are separate legal entities (501C3 nonprofit organizations in the United States and registered charitable organizations in the United Kingdom). SHOs can be contrasted with the semi-dependent consumer-operated “partnerships” whose governance and administration is controlled by professionals or bureaucrats (Davidson, Chinman, Kloos, Weingarten, Stayner, & Tebes, 1999; Solomon & Draine, 2001).

Whether present in informal groups or funded organizations, self-help/mutual aid can be seen to have the following seven elements commonly recognized as essential:

- (1) people with a similar illness, condition or status, who meet, physically or virtually;
- (2) voluntarily and intentionally;
- (3) controlling and owning their own interaction (self-directed leadership);
- (4) to resolve or improve their own shared problem or situation through;
- (5) valuing experiential knowledge; and
- (6) reciprocal mutual aid (7) that is given freely without fees (Borkman et al., 2005, pp. 9-10; see also Humphreys, 2004).

LITERATURE REVIEW

The growing literature on SHOs in the United States was reflected in three main reviews (Campbell, 2005; Davidson et al., 1999; Solomon & Draine, 2001). A British review (Rose, Fleischmann, Tonkiss, Campbell, & Wykes, 2002) systematically reviewed research on user participation in the United States, Canada, and England and found that SHOs were too new in England to be reported in the literature (Rose et al., 2002, p. 76) but suggests that much can be learned from the United States and Canadian experiences (Rose et al., 2002, p. 17).

The three U.S. reviews covered the same studies and consisted primarily of surveys of service users' experiences. Only 3 of 24 studies detailed by Campbell (2005, pp. 46-57) dealt with the group or organizational level of analysis (Emerick, 1990; Rappaport, Seidman, Toro, McFadden, Reischl, Roberts, et al., 1985; Van Tosh & del Vecchio, 2000); the latter two, however, dealt with SHGs rather than SHOs. Van Tosh and del Vecchio (2000, p. 77) reported how 13 of 14 demonstration projects funded between 1987-1992 by the federal Community Support Program of the National Institute of Mental Health had begun as semi-dependent "partnerships" with state mental health agencies, but by the end of funding 90% had achieved operational control and legal status as SHOs.

Clay (2005) documented eight SHOs funded by the federal U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) from 1998 to 2002; case studies of SHOs were written by the service users who developed and lived in them day to day (p. 3), describing the evolution of the programs, the internal workings, barriers to overcome, and kinds of services provided. Four were drop-in centers, two peer-support and mentoring services, and two educational/advocacy programs.

Eight core ingredients regarded as fundamental to all peer-run programs were identified within a longer list of 26 aspects found among the three types (Clay, 2005, p. 7). While the eight core ingredients overlap substantially with elements of self-help mutual aid, a surprising omission was experiential knowledge. Many researchers, service-users, and practitioners, among them Riessman and Carroll, think that experiential knowledge is a critical aspect for service-users: "The taproot of consumer empowerment is its validation of experiential knowledge and the expertise born of 'being there'" (Riessman & Carroll, 1995, p. 126).

In addition to research reviews, three theory-based studies of service user-run organizations were located (Felton, 2005; McLean, 1995; Nelson, Lord, & Ochocka, 2001). Two of these were in-depth ethnographic case studies, both in a northeastern U.S. city: McLean (1995) studied Quad, a drop-in center and Felton (2005) observed a consumer-run agency using the community narrative framework of Rappaport (1993, 2000). McLean found discrepancies between the self-help peer philosophy and the practice of directors who alienated participants

by behaving as professional providers rather than peers. The directors, both professionally trained and mental health consumers, were not cognizant of the consumer self-help philosophy and acted in terms of their professional training. Felton's case study also identified participants who were steeped in the service user movement philosophy and others who were unaware of it.

Two English articles on SHOs, not mentioned in the Rose et al. (2002) review, were written by their project managers (Fox, 2004; Jenkinson, 2004). Neither article was based on empirical research but recorded their experiences of working with mainstream professionals. Jenkinson (2004) described her negative experiences leading to the SHO's policy of non-involvement in any partnership scheme with mainstream workers. Fox (2004), on the other hand, while insisting that only service users had voting rights on the governing board, recognized the helpful contribution of three advisory board members. From these different accounts, the relationships with professionals seemed influential in determining whether the SHO developed as an alternative or a complement to mainstream services.

The only cross-national comparative study of SHOs that we could locate was the one we had written (Borkman et al., 2005), case studies of the SHOs described here (with the exception of Freedom) as well as a Fountain House clubhouse in Sweden were presented and compared within a cross-national context.

SHOs' RELATIONSHIPS WITH FUNDERS

Self-help/mutual aid is strikingly different from professional help, and government funders usually operate in terms of professional helping paradigms (Borkman, 1999; Riessman & Carroll, 1995, pp. 35-37; Smith & Lipsky, 1993; Wilson, 1995). With professionals, the client is in a subordinate position; help is a commodity that is paid for; the helping is one-way; the goals and direction of help are largely controlled by the professional; the help giving is usually highly structured in place and time; and the knowledge is professional based on education and credentials (Borkman, 1999, pp. 85-93; Riessman & Carroll, 1995, pp. 35-37; Wilson, 1995).

In contrast, Howie the Harp, long-term mental health service user and leading activist, describes self-help services as:

Everyone is equal in power; clients control their individual services, and nothing is done against their will. Clients control the agency in which services are provided; the consumers providing services are role models who understand what clients are going through; clients are recognized as the "real" experts. People are treated with dignity, respect, and fairness; there is tolerance and patience for different types of behavior, including "difficult people"; people are not dealt with clinically or in terms of a diagnosis. Services deal with practical needs and provide practical support; the goal is not cure or adjustment but improving the quality of the individual's life (Riessman & Carroll, 1995, pp. 125-126).

The multiple tensions arising from the acceptance of government funding by SHOs is conceptualized in Felton's (2005) case study in terms of being an insider/outsider. As an *insider* in mainstream mental health services the pressure is to comply with mainstream practices and ethos while occupying the *outsider* status and trying to maintain integrity as a peer-run program. The insider/outsider idea is, from the perspective of the SHO participants, analogous to Third Sector research (Milofsky, 1988; Salamon, 2002; Smith & Lipsky, 1993) which considers the same issues but from the perspective of an "objective" observer standing outside the mainstream system and its alternatives.

Despite the growing literature on mental health SHOs, most particularly in the United States, the emphasis has been largely on the effectiveness (or otherwise) of SHOs. While this has been important in endorsing the ability of service users to provide their own services, equally important is the need for a better understanding of the core features of SHOs and the impact that funding has on preserving or diluting those features.

In order, therefore, to examine whether SHOs funded by local government lose their self-help/mutual aid focus as predicted by the Third Sector literature and cautioned by mental health activists, we asked the following specific questions.

1. How do the origins of the SHOs affect their philosophy and relations with funders?
2. How and to what extent are the organizations based on self-help mutual aid?
3. Do SHOs regard their program as a complement to mainstream services, an alternative, or something other?
4. Do SHOs' leaders view the government funders as constraining or facilitating their peer-run activities and philosophies?

METHODOLOGY

The impetus for this study arose from the authors' commitment to working with SHGs and more recently, with SHOs. Research on SHGs and SHOs is most effective when it is participatory; the core methodology in this research is based on a case study approach (Denscombe, 1998, p. 30) which typically provides rich descriptive data identifying unique and complex features of the chosen cases (Parahoo, 1997; Yin, 1994). It is also a useful methodology for theory building, refining theories, and establishing the limits of generalizations (Stake, 1998, p. 104). For these reasons, the case study approach was adopted.

The methods and findings discussed below relate to the first phase of a larger comparative study (Borkman et al., 2005) and are focused on three case studies in the United States and two in England.

Methods and Data Collection

A variety of methods were used including semi-structured interviews, focus group meetings with research participants (England), observation of a board meeting (United States, detailed field notes (United States), and analysis of “grey literature” including policy documents, publicity material, and reports produced by the SHOs. In both countries, time was spent visiting the SHOs prior to the commencement of the study and all research procedures, including gaining written consent from participants, were approved by the respective University Ethics committee.

Sample

To focus on organizational features not associated with unsettled, newly organizing groups, a SHO had to be in existence for at least 3 years to be included in the study. An East Coast state in the United States was selected for accessibility, with 20 SHOs which were provided technical support by the same umbrella organization. From the 20 SHOs, a purposive sample was selected using the criteria of area (rural, suburban), size (over 300 members, under 20 members), and service characteristics (formal drop-in, informal self help).

Mental Health SHOs are relatively new to England, so the two case studies were selected in relation to an area with a strong tradition of self-help/mutual aid and supportive infrastructures (Midlands) and an area with less of a tradition of self-help/mutual aid (South East). At the time of the study, the two SHOs chosen were, to the authors’ knowledge, the only mental health SHOs in either area.

Interview Data

A semi-structured interview schedule was used, but during the interactive process of data collection and interpretation this was modified by the respective countries in order to take account of policy and funding differences. However, the main themes were the same and included:

- History and development of the SHO;
- Membership;
- Governance features;
- Perspectives toward mental health;
- Services and support provided; and
- Relationships with funders, government agencies and other organizations.

Interviews lasted approximately 1 hour. As they were not tape recorded, two researchers were present—one asking questions and the other taking notes—whenever possible.

The number of interviews varied with the size of the SHO, but in all cases the directors and at least one board and one staff member were interviewed.

In England, 12 interviews were carried out (7 females, 5 males, all white). There were also 12 interviews with directors, board members, and staff in the three United States case studies (9 female, 3 male: 7 white and 5 African Americans).

Data Analysis

All data collected were analyzed in relation to the main themes listed above and written up as case studies. These cases were comparatively analyzed by the researchers, initially by e-mail and then during a 3-day face-to-face meeting. This time-consuming process was critical to ensure that sufficient time was devoted to reflecting on the cultural differences and assumptions. In the light of these reflections, we constantly revised the meanings of our comparative analysis (Stake, 1998, p. 99; May, 2001).

Validity Checking

It was in the process of validity checking that procedural differences arose. The researchers were committed to participatory research and aware of the growth in user-led research (Chesler, 1991; Isenberg, Loomis, Humphreys, & Maton, 2004; Kaufmann, 1994; Weaver & Nicholls, 2001). In England this growth together with the service user movement's critique of traditional research (Beresford, 1999; Turner & Beresford, 2005) resulted in participants wishing to be actively involved in the validity checking process. In the United States, although the umbrella organization was invited several times to form a steering group and comment on draft copies of the interview schedule, they chose not to do so.

In England, participants were sent transcripts of the interviews, resulting in feedback both on points of accuracy and in providing additional data. The interview data thus validated the case studies which were written and sent to the participants along with an invitation to a focus group. This process with participants acting as a peer support group for maintaining credibility (Ely, Anzul, Friedman, Garner, & McCormack Steinmetz, 1998; Lincoln & Guba, 1985) again provided additional data. Finally, the revised case studies were sent to all participants; at this point validity saturation occurred, and no further comments were received.

The U.S. process was equally rigorous using a process of triangulation to check the data against different sources (for example, interview data with grey literature). The data were then discussed and validated between the two researchers (Stake, 1998, p. 87). The researchers came from different cultural backgrounds (United States and Sweden) and frequently questioned each others' interpretations, illustrating the importance of peer review especially in cross national studies.

THUMBNAIL SKETCHES

To set the context for the results, we begin with an overview of the commonality of SHOs within a country followed by a thumbnail sketch of each SHO; all SHOs have been given pseudonyms.

U.S. SHOs

The three U.S. SHOs were located in the same East Coast state and were loosely affiliated with an umbrella mutual support SHO (Just Us) that had a contract with the state to provide technical assistance in board development, financial management, and organization. The umbrella SHO also engaged in legislative advocacy, provided speakers on mental health topics, held an annual conference that brought together members from all SHOs in the state, and acted as an intermediary with the state or mental health providers.

The funding for all three SHOs was provided by the state mental health agency and was distributed by each county's Core Service Agency (CSA); CSAs were county specific—either quasi-governmental nonprofit or county—and selected the SHOs to fund and monitor. The state's guidelines specified that the SHOs had to be legally constituted nonprofits 501C3, with auditing and reporting requirements, as well as particular requirements for consumer run organizations. The peer support items had been designed by a mental health consumer working in the state's mental health Office of Consumer Affairs and included the number of: hours the center is to be open, consumers served, peer support meetings, outreach educational sessions to service users in hospitals or clinics, and activities "designed to promote development of natural support networks and reduce isolation." Despite the funders' requirements, there was noticeable diversity in how the SHOs operated. All SHOs were led by dynamic women whom our Swedish researcher called "Fire Spirits."

Promise

Promise was initiated in 1999 as a drop-in center for the homeless mentally ill, as a result of collaboration between a CSA funder, service user, and two sympathetic professionals. In 2001 it became a SHO. The drop-in center, located in a medium-size, old industrial city, was open 7 days a week for 3 hours a day. It provided showers, laundry, an address, computers, support groups, and leisure time activities. Of the SHOs we studied, it had the largest budget (state and federal funding) and served the most people (350 per month) with nine staff and four volunteers; moreover, it had extensive electronic and transportation linkages with mainstream social service and health agencies. Staff were trained as service user case managers. As a drop-in center, it resembled a service agency more than a service user run facility. The demographics of Promise's participants who were all homeless with diagnoses of mental illness were estimated as: 80-90% male, mostly African American, between 25-20 years of age, 5-20% were employed.

Just Us of J County

Just Us of J County was a small organization founded in 1992 by the local CSA funder and service users working together. It had lost 2/3 of its funding due to irregularities on the part of the previous directors and had no paid staff. Its activities were a drop-in center—open 3 days a week— a mutual help group, and one or two special events a year. It was located in a suburban area in a church, inconvenient to public transportation. All attendees were also board members and the SHO resembled a self-help/mutual aid group. All work was done by volunteers.

The 15 regular attendees were role models and mentors for each other; another 150 on their newsletter's mailing list attended the occasional special events. The demographics of J County's participants, all of whom used mainstream mental health services, were estimated as: 40-50% male, 50% African American, and 50% white, 75-80% between ages 25-50, 75% or more collected disability payments, and 10-30% were employed.

Freedom

Freedom was initiated as a self-help/mutual aid group in 1993 by a female service user and received state funding as a drop-in center. It hosted several mutual help groups and had a small consumer-run business also funded by the state that hired two service users to assist with shopping, medication, or transportation to appointments. Located in a storefront on the main street of a small town, it served 100 people with four staff and 10-15 volunteers. It published a yearly magazine of poems, stories, and artistic expressions contributed by service users from all over the state. The demographics Freedom's participants who self-reported having used the services of mental health professionals were estimated as: 35-40% male, 90% white, 10% African American, 75-80% between the ages of 25-50, 10% over age 50, 50-75% collected disability payments, and 25% were employed.

English SHOs

The two SHOs are independent of any other organization and are funded by separate local governments based in different parts of England. One, in the middle of the country, had a strong tradition of self-help/mutual aid activity; the other, in the South East of England, is in an area known for developing user-led initiatives. Both SHOs have been in existence for over a decade and provided support to other service users before acquiring additional funding. Both SHOs contribute representatives to Service User Forums established by mainstream services to develop local mental health policy.

Live

Live began as a self-help/mutual aid group in 1993 and became a SHO 2 years later, gaining charitable status. It provided a range of services: a drop-in center, a crisis helpline, advice and information services, as well as a variety of peer groups. It was located in a detached building which it shared with other voluntary organizations within walking distance of a medium-sized city in the South East of England. Core funding was provided by government resources, although other charities supported some of its services. It had a membership of 201 and provided services through 7 paid staff and 14 volunteers. Live was active within the local community in promoting mental health awareness by means of a range of activities including drama. Fifty-five percent of its members were males and 75% lived in the city. Demographic details on age, ethnicity, and employment were not collected as the participants did not wish such information to be released.

Advocates First

Advocates First had been operating as a SHO since 1987 and evolved from an alliance between service users and radical professional and academic activists. It provided advocacy for individuals and groups. In addition, it provided a number of community development initiatives such as the purchase of a trailer house for use by members and their families who could not otherwise afford a holiday. Advocates First was located on the outskirts of a medium-large urban city. Local funding supported its core services and it raised additional income from specific advocacy projects. It had five paid staff and ten volunteers and a membership of 150 people. As one of the first advocacy services in England, it had provided training for other advocacy SHOs in the country. No demographic details on the 150 members were available.

RESULTS OF THE STUDY

How Did the SHOs Originate?

Participants recognized the significance of sympathetic professionals in providing support and, in some cases, funding. The complex and nuanced relationships between service users and non-users stood in contrast to many of the findings reported in U.S. literature which tend to posit a simplistic and polarized relationship between self-helpers and professionals (Chesler, 1990; Gidron & Hasenfeld, 1994; Katz & Bender, 1990) and to reports in the British professional literature which “appears to ignore the important role of professional user involvement ‘champions’” (Rose et al., 2002, p. 13).

In the United States, two of the three SHOs (Promise and J County) were initiated by the CSA funder representatives along with interested service users and others. The funder representatives for Promise was a social worker who was

very knowledgeable about 12-step self-help groups, assisted by sympathetic professionals. Just Us, the umbrella advocacy organization, assisted J County service users and the CSA funder. The third U.S. SHO, Freedom, was initiated as a self-help/mutual aid group 5 years before it became a SHO by a woman who participated personally in 12-step groups; a CSA funder provided funds to transform the SHG into a SHO.

Both English SHOs had evolved from self-help/mutual aid activities. Live started as a self-help/mutual aid group meeting in their founder's home. Their impetus was concern about the lack of information available both for people with mental health problems and their families. Advocates First began as an alliance between service users in a Patient's Council and local mental health activists. In different ways, sympathetic professionals had acted as facilitators for both SHOs in terms of assisting them in obtaining funding and encouraging/supporting them as they developed their services. For example, the founder of Live worked with another service user who was employed by the statutory services to develop service user participation in mainstream services. Together they established extensive networks with other sympathetic professionals and service users which were instrumental in Live obtaining further funding and ultimately charitable status.

Advocates First's evolution involved a wider group of people committed to the advocacy movement. The service users at Advocates First were originally based in a hospital service and were part of a wider group of people (professionals and academics) working for empowerment and advocacy for people with mental health problems, using mainstream services. Both SHOs can be seen to form part of the U.K. Service User Movement. Additionally, Advocate First had international links with advocacy workers in Holland who were inspirational in the development of their work.

How and To What Extent Do Leaders/Staff Believe In and Use Self-Help/Mutual Aid Principles?

The self-help/mutual aid ethos including experiential knowledge was seen as the dominant, if not unique, feature of SHOs in both the United States and England. Despite differences in origins and funding, the mutuality ethos transcended the existence of peer groups and was embedded in the very fabric of the organization itself.

In the United States, all three SHOs used peer support principles extensively in their drop-in centers: formal self-help groups; a safe place to share stories with peers, developing friendships and helping relationships; social activities; and volunteering opportunities. Two of the three SHOs (Freedom and J County) consistently spoke about the importance of experiential knowledge and peer support. The third SHO was mixed: Promise's leadership defined self-help/mutual aid narrowly in terms of self-help groups and did not mention experiential

knowledge as a resource; in contrast, Promise's staff thought that the most important aspect of their service was "to provide peer support and the 'we've been through it' perspective." Ironically, Promise's funders' representative understood peer support better than its director.

The similarity between the English SHOs was most marked in the importance that board members and staff attached to experiential knowledge, peer support, and the self-help/mutual aid ethos. As one (female) participant observed:

Our greatest resource though is our experiential knowledge, because whatever our opinions about mental health may be, we have all been there and in this sense our experience is universal. We know what is likely to be helpful when someone is dismissed. I think this gives meaning and value to our own experiences.

Besides the peer activities, story telling, and "being there for one another," the self-help/mutual aid ethos was exemplified in the way that both SHOs normalized mental distress and were committed to retaining a sense of mutual support and flexibility within the organization. For example, if someone was having mental health problems others would be expected to help by supporting that person (such as visiting them in the hospital) and, where appropriate, taking on their work responsibilities.

Are SHO Services Regarded as a Complement to Mainstream Services or an Alternative?

A similarity of the SHOs in the United States and England related to their views as constituting complements to, and part of, the mainstream mental health services. This stance is in contrast with the radical positions popular in the 1970s and 1980s in which anti-psychiatry movements of service users were substantial; Chamberlin (1978) and others argued for independent and alternative user services as they could not imagine acceptable services emanating from within the mainstream.

Promise's directors saw their services as a supplement to professional services linking the homeless mentally ill to mainstream professional social, welfare, and health resources. They saw themselves as integrally related to the mainstream system, and as a place where professionals could connect with clients. In contrast, Freedom and J County participants and Promise's staff also saw their SHOs as complements to professional services, but they emphasized the distinctive role of their SHO in providing peer support, role models, assistance with individual advocacy and the "we've been through it" perspective. Freedom's director said: "We are the second to the last link in the chain: Hospital-Rehabilitation-Freedom-Independence." No one expressed an anti-psychiatry or anti-professional view as was seen in the radical phase of the service user movement in the 1970s and 1980s. Probably everyone would have agreed with

the statement: “People with mental illness need professionals, but also need their peers.”

Both English SHOs conceptualized themselves as a complement to mainstream services. For Advocates First this was an issue that had caused serious tension in their organization’s development. Having begun as an advocacy organization, a fracture/chasm had occurred between those who sought to establish closer “partnership” working relationships with mainstream services and those who wished to retain lobbying activities aimed at changing services. The shift toward the former model had resulted in the resignation of some staff and volunteers. In Live, a similar tension existed with some participants highlighting the importance of the SHO creating a safe haven for people who did not either fit or wish to fit in with the values of mainstream services and society; others, however, voiced concern at the potential for the SHO to become “ghettoized” and wished to further integrate the organization with the local community.

A dilemma for both English SHOs was the sheer amount of time they spent acting as “representatives” of service user groups in Forums instigated by mainstream providers.

How Do SHOs’ Leaders View Government Funders?

Government funding was primarily beneficial to the SHOs in both countries despite service users belief that the funders probably did not understand their ethos very well, or the minor complaints over paper work or extensive reapplications for funding. The benefits of funding stemmed from different sources: the self-help/mutual aid requirements of SHOs in the United States had been designed by mental health consumers who understood the ethos and technical assistance provided for organizational development. In England, local authorities only funded well-developed SHOs with good reputations and specified no performance requirements.

All U.S. SHOs reported organizational and board member developmental help from the funders. In contrast, the English SHOs received no technical support from their funders which meant that the co-ordinators and staff were expected to have a range of skills and expertise in areas such as strategic planning, management, budgeting, and human relations. They had to ensure that these skills were present or built within the organization by either staff or Board Members.

In the United States, all the funding came from one state through county specific CSAs whose interest it was to help the SHOs succeed. All three of the U.S. SHOs acknowledged that their funder set their objectives and procedures which included the state’s bureaucratic requirements of keeping records, an auditor’s report, and specified peer support activities. Paperwork was the only requirement mentioned as detracting from doing peer support, but interviewees were not angry or frustrated regarding this matter. Promise’s Director, who saw her SHO as a hand maiden to professional services, expressed the most compliant attitude about

funders: "The guidelines are pretty open . . . and are not that stringent. We just do whatever they say." All three SHOs maintained they had a good or positive relationship with their funders. Participants in all three SHOs thought the funders understood somewhat, but not extensively, principles of self-help/mutual aid. Freedom's Director was the only one who offered examples of how funders failed to truly understand self-help principles.

In England, the major source of funding for both SHOs was derived from local government. Live had also acquired Lottery Funding and monies from various charitable organizations; Advocates First had acquired supplementary income from specific advocacy contract work and training projects. Both SHOs recognized the significance of having evolved from user-led activities where they held a strong vision of the type of service they wished to develop. Thus, they felt initially that funders were prepared to resource their vision and continued to do so because they were well-established and had a good local reputation. Consistent funding over the years had given both organizations the opportunity to develop. Both SHOs were concerned about the potential constraints of future government funding considering relatively new national policies (e.g., Department of Health, 2004) that may mean that local funders may only be able to resource services that have been deemed a national priority. There was also concern that not all funders understood the philosophy of the organization, as a male comments:

The essence of drop-in is . . . they (funders) see . . . is a big smoky room. Funders don't see the priceless stuff, all the contacts for the week and how people interact with each other.

In common with other voluntary organizations there was a disproportionate amount of time taken to re-applying for funding, which seemed to act as a deterrent to developing a wider vision for the SHOs.

DISCUSSION

The Consumer/Survivor/Service User Movement in the United States and the United Kingdom is influenced both by developments in mental health policy and by the evolution of SHOs. SHOs are, in and of themselves, symbolic of the success of service users in affirming a range of hitherto denied abilities. Certainly, the case studies revealed many of these abilities, such as leading organizations, contributing to their development, role modeling, artistic expression, and peer advocacy. In the United States, there are nearly twice as many service user run alternative organizations as mainstream services; but, with important exceptions, there is comparatively little involvement of service users in the development and provision of mainstream services. In England, because of the proliferation of service user forums and advisory groups as well as individuals' input to their own

care planning within mainstream services, SHOs still represent a relatively new phenomenon (Rose et al., 2002).

Professionals have been involved in all of the SHO case studies but have taken different roles in their founding and development. In both English SHOs, service users have instigated and led the vision and ethos of the SHO, typically in response to concerns about the nature or adequacy of existing service provisions. In England, Live formed alliances with professionals to assist them in realizing their pre-existing vision of service provision. The role of professionals in Advocates First was multi-faceted and spanned the founding and early development stages of the organization before it was staffed entirely by service users. In the United States, the funders' representatives were professionals and some understood self-help/mutual aid more than some of the SHO directors; professionals helped develop all three SHOs.

In England, does the constant role of service-user/advocate in policy forums keep alive the emancipatory vision of the social movement, or is it mostly tokenism (Rose et al., 2002)? In the United States, SHOs are being funded by governments on the government's own terms; and, in this study, the mental health service users accepted the government's requirements with only slight complaints about the paperwork. Will the U.S. service users develop amnesia (McLean, 1995) and allow themselves to accept whatever terms government wants?

Despite the policy differences, SHOs in both countries face similar tensions in terms of their identity and autonomy as a service when they are funded by the mainstream, while holding an ambiguous relationship to mainstream provision. Perhaps the most marked tension is exemplified in SHOs' relationships with funders. As Chamberlin warned in the 1970s, the moment a community of supportive peers becomes a funded organization, it is immediately straddling two potentially conflicting roles as both provider and recipient of services. While acknowledging this tension, Felton, writing in 2005, is more optimistic about the potential for SHOs to resolve the dilemma by developing and maintaining a vision of the organization through a collective narrative in which the uniqueness of the SHO is consistently reinforced.

In our cross national study, it was apparent that the origins and vision of a SHO had a marked influence on its ability to manage this inherent tension. For example, both English SHOs had developed a strong vision and value base for their organization before they sought funding to enhance their services. However, there was a fear of losing their direction as their growth and sustainability became more dependent on state funding. In some of the U.S. case studies, knowledgeable funders were largely responsible for instigating the SHOs and maintaining their vision. These examples epitomize Felton's insider/outsider dilemma where SHOs are reliant on "outsiders" for their funding but do not wish them to take control and where "funders" are seeking to draw SHOs into mainstream services and society.

What funders may not see or fully appreciate is the centrality to SHOs of the self-help/mutual aid ethos and especially the experiential knowledge of service users. It is striking that, despite different policy, cultural, and national contexts, the SHOs identified a range of similar self-help/mutual aid features and practices as fundamental to their organizational culture. These characteristics were a feature of their governance, belief system, and practices. Underpinning this ethos was the importance attached not only to the individual's experiential knowledge but also to the experiential knowledge of the collective. The government funded and service user led study of U.S. SHOs (Clay, 2005) identified similar features with the exception of experiential knowledge. Was experiential knowledge "forgotten" because the study was government funded and supervised by professionals working for the government? It is noteworthy that our data and others suggest that these features can still be seen as fragile especially where funders do not recognize their centrality to the vision and functioning of the SHO.

Despite this fragility we found positive impacts associated with government funding of SHOs in both countries, unlike the evidence presented by much Third Sector research (Smith & Lipsky, 1993). In England, local governments were willing to fund the self-help/mutual aid vision of well established SHOs with good community reputations and did not compromise their principles by leveling requirements that would have distorted their ethos or practices. In the United States, perhaps by chance, a mental health consumer working in the state Office of Consumer Affairs had designed the state requirements for SHO's activities. Thus, the funding requirements provided the opportunities for self-help/mutual aid to flourish, which it did in all the SHOs, including the ones where either the directors or the funder's representative had limited understanding of self-help/mutual aid. One cannot assume that all government funding will produce such fortunate outcomes.

CONCLUSION

Our research to date suggests that SHOs are walking a tightrope, one on which they can successfully retain their self-help/mutual aid ethos even when professionals and funders are involved. For this to be achieved, a balancing act is required which involves professionals being empathetic to and understanding of the centrality of experiential knowledge and of the ability of service users to successfully provide services. While acknowledging the limited financial capabilities of government and the necessity to maximize all resources, funders need to respect the vision and ethos of SHOs and not impose upon them inappropriate government priorities and targets. Felton's (2005) concept of the insider/outsider is a useful way to conceptualize the tension but runs the risk of polarizing insiders and outsiders whereas our data suggests more nuanced relationships. There is movement on both side—empathetic professionals who

wish to both develop mainstream services and support SHOs and users who wish to change the mainstream and develop genuine complements or alternatives.

In order for us to understand the complexity of this relationship, we need more research on the variety of governmental funding arrangements and their impact on the integrity of self-help/mutual aid, and why some SHOs succeed and others fail. Is it due to external demands of funders and policy makers or the SHOs own inherent strengths (e.g., leadership) and/or vulnerabilities? This suggests the need for longitudinal research which looks in detail at the various stages and processes involved in SHOs' history and development.

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