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Self Help Organizations: A Survey of Services Provided by Polio Organizations*

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Abstract

This paper reports on a survey of self-help polio organizations in the English-speaking world. While the organizations varied greatly in size (7 to 9000) and structure, the organizations were similar in terms of the services they provide polio survivors. Most kept members up-to-date about medical research on post-polio syndrome and provided opportunities for social interaction and sharing their experiences. Most organizations were affiliated with either other polio organizations or hospitals and clinics. Generally, these organizations operated on limited funds with most of the funds paying for newsletters and meetings.

Introduction

Numerous organizations have formed in response to diseases and health related issues, including cancer, heart disease, AIDS, birth defects, diabetes, head injuries, and drug addiction. In this paper we report polio survivor organizations. A unique aspect of polio, compared to other disease oriented organizations, is that polio has been virtually wiped out in the industrial world. These organizations are unique in that their potential membership pool is not being replaced as it is with organizations dealing with such diseases as cancer, heart disease, or AIDS.

The Sample

The sample of organizations was obtained through a list compiled by *The International Polio Network Directory - 2000*. Questionnaires were sent to 200 organizations in the U.S. and 20 organizations in five English-speaking nations. A total of eighty-three (83) usable questionnaires were returned - the United States (74), England (3), Australia (3), and New Zealand (3).

When founded?

The oldest organization is in England and was founded in 1939. The next oldest was founded in 1975 in California, followed by a Kansas organization in 1976, and another California group in 1978. Half the organizations started in the 1980s with 1985 and 1986 reported as the most frequent years. The newest organization in our sample was started in 2001 in Florida. The Australian organizations started between 1989 and 1992, about the same years as the New Zealand organizations (1986-89). The second United Kingdom organization in the sample started in 1996.

Table 1: Date organization was founded

Year	*N*	*Percent*
1939	1	1.2
1975	1	1.2
1976	1	1.2
1978	1	1.2
1980	1	1.2
1982	2	2.4
1983	1	1.2
1984	3	3.6
1985	11	13.3
1986	8	9.6
1987	5	6.0
1988	6	7.2
1989	8	9.6
1990	3	3.6
1991	5	6.0
1992	1	1.2
1993	8	9.6
1994	3	3.6
1995	2	2.4
1996	2	2.4
1997	2	2.4
1998	3	3.6
1999	2	2.4
2001	1	1.2
Total	81	97.6
Missing	2	2.4
Total	83	100.0

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Nearly half (48%) have filed as non-profit organizations. Similarly nearly half (44%) of the organizations have an official mission statement (see table 2).

Table 2. Formal status of organizations

Non-Profit?	*N*	*Percent*
No	41	51.9
Yes	38	48.1
Total	78	100.0

Mission statement?	*N*	*Percent*
No	45	55.6
Yes	36	44.4
Total	81	100.0

Size of membership

The organizations ranged in size from seven (7) to nine thousand (9000). The mean size was 367 with a much lower median (110). When the organization with 9000 was removed, the largest organization was 1,700 with a mean of with a mean of 249 and median of 106. One fourth of the organizations have thirty-six (36) or fewer members. Membership is not well defined. Since many of these organizations don't charge dues (or are lax in collecting them), somethey define their membership by those on a mailing list.

The average meeting attendance falls far short of people on the organizations' membership/mailing lists. Meeting attendance ranges from 4 to 110. The mean is twenty-five (25) with a median of eighteen (18).

Relationships to other organizations

Inter-organizational relationships abound within the polio community. Seven in ten are affiliated with another polio organization (69.9%), one in four (25.3%) are affiliated with a hospital, and one in six (15.7%) with a polio clinic (see table 3).

The hospital and clinic associations are to be expected. Polio left many of its survivors with various deformities and health problems. In recent years, many of the survivors have started experiencing additional health problems, referred to by such terms "post polio syndrome" and "post polio sequelae" (Bruno 1998; 1991; Bruno and Frick 1991; Jubelt and Cashman1987; Halstead 1998).

Table 3: Affiliations with other organizations

Affiliated with	*Percent*	*N*
Another polio organization	69.9%	58
Hospital	25.3%	21
Polio Clinic	15.7%	13
Two of above	10.8%	9
All three above	8.4%	7
None of the above	15.7%	13
Total	100.0%	83

Where are meetings held?

The meetings are held in a variety of places. Hospitals and clinics are most common with nearly a third of the organizations holding meetings at these sites. Community buildings, social services facilities, restaurants, and even members' homes are used as meeting sites (see table 4).

Table 4: Where meetings are held

Hold Meeting at ...	*Percent*	*N*
Community Building	24.7	20
Hospital/Clinic	32.1	26
Church	11.1	9
Restaurant	9.9	8
Easter Seals	8.6	7
Other Social Service	8.6	7
Members home	8.5	7
Office Building	3.7	3
Other	16.0	13
Total *	116.9	81

* Some organizations meet in more than one place

Table 5: Frequency of meetings

Frequency of meetings	*Percent*	*N*
twice monthly	2.4	2
Monthly	58.5	48
Quarterly/bi-monthly	35.4	29
Less than quarterly	3.7	3
Total	100.0	82

Meeting frequencies and times

Over half of the organizations hold their meetings on a monthly basis with another third having either quarterly or bi-monthly schedules (see table 5).

Over half the organizations hold their meetings on Saturday (see table 6). The next most popular days are Sunday and Monday with only one organization having Friday meetings. Mornings and afternoons were the most popular times for the weekends with evenings being more popular on weekdays.

Table 6: Day of meetings

Day of Week	*Percent*	*N*
Monday	9.3	5
Tuesday	5.6	3
Wednesday	7.4	4
Thursday	3.7	2
Friday	1.9	1
Saturday	59.3	32
Sunday	13.0	7
Total	100.0	54

Table 7: Time of day meetings are held

Time of meetings	*Percent*	*N*
morning	28.6	22
noon	10.4	8
afternoon	37.7	29
evening	19.5	15
other	3.9	3
Total	100.0	77

Who Plans the meetings?

In nearly half (46%) the organizations, the president/coordinator is solely responsible for planning the meetings. Fifteen percent (15%) of the organizations have a formal planning committee. The remaining 40% is largely a combination of various people, many of which include the president (see table 8).

Table 8: Who plans the meetings?

Who plans the meeting?	*Percent*	*N*
President/Coordinator	45.1	37
Planning committee	14.6	12
Other	40.2	34
Total	99.9	82

Notifying members of meetings

The organizations use a variety of communication channels to announce their meetings. Three of four use newsletters. Other direct communication channels include post cards, phone calls, and e-mail. Newspapers are the most used media source with half using this method. WEB pages, radio, and TV are used less frequently.

Table 9: Methods used to notify members about meetings

Meeting announcements	*Percent*	*N*
Newsletter	75.6	62
Post card	20.7	17
Newspaper	51.2	42
Radio	9.8	8
TV	7.3	6
WEB	14.6	12
Other	30.5	25
Total *	210.5	82

* many organizations used multiple methods

Meeting activities

Medical/health care speaker and sharing experiences are the most common meeting activities. Speakers on technical aids, social service benefits, and working to change laws are uncommon meeting activities (see table 10).

Table 10: Meeting activities

Activity	< Half	Half	> Half	Favorite	Top two
speaker medical	37.2%	20.5%	42.3%	56.3%	79.7%
speaker technical aids	86.8%	10.5%	2.6%	0.0%	15.6%
soc serv benefits	93.5%	1.3%	5.2%	3.9%	5.5%
share experiences	37.7%	14.3%	48.1%	25.0%	56.3%
social gatherings	75.6%	11.5%	12.8%	15.6%	39.0%
change laws	89.5%	3.9%	6.6%	0.0%	1.6%

In addition to being the most popular activity, two thirds of the organizations report that medical speakers increase attendance at meetings. While sharing personal experiences is the second most preferred activity, one in five organizations report that meeting attendance is down when discussions are the primary or only activity. Other factors reported to affect meeting attendance included seasonal migration and weather. Some organizations plan their annual schedules to the degree that they might not have meetings during months many members are gone or when the weather is likely to be bad (e.g., ice and snow in Northern states) (see table 11).

Table 11: Meetings with larger attendance

Type of meeting	*Larger attendance*		*Smaller attendance*	
	Percent	*N*	*Percent*	*N*
Speaker	66.7	52	2.6	2
Party	5.1	4	2.6	2
Migration	1.3	1	1.3	1
Discussion	2.6	2	20.8	16
Other	10.3	8	37.7	29
None	15.4	12	36.4	28
Total	100.0	78	100.0	77

Litvak and Martin (1999/2000) noted that among disabled persons transportation is a major problem, especially in non-urban areas. This helps explain why some of the organizations reported in this sample do not schedule meetings for months when inclement weather is expected.

Gaston and Meissen (1999/2000) reported the following problems as common among self-help groups: attracting new members, getting members involved in the work, overworked leaders, getting members to attend meetings, and retaining members. Many of the polio organizations depend on both the donations of time and economic support from their leaders. Three organizations in our sample recently disbanded, two due to declining membership and one because the president died and no one was willing to undertake the responsibilities.

Newsletters

Seventy percent of the organizations publish a newsletter. They publish from two to twelve issues each year with the most common schedule being four issues per year. The size ranges from one to twenty-four pages. From 20 to 1850 copies of each newsletter are printed. Like the rest of society, a number of the organizations are moving into Cyberspace. Nearly half the organizations have e-mail addresses and thirty (30) percent have WEB sites.

Table 12: Characteristics of Organization Newsletters

Of the 70% that publish a newsletter	*Mean*	*Median*	*Range*
Issues / year	7.05	6	2 - 12
Pages / issues	7.86	7	1 - 24
Number printed	403	220	20 - 1850

Madara (1999/2000) noted that computer technology is able to reduce barriers that previously kept persons desiring mutual aid apart. For example, those who are home-bound are now able to converse with others having similar problems. On-line self-help has been found to provide similar benefits to face-to-face self-help. Currently a majority of the 100 largest self-help groups have web sites and/or e-mail addresses.

Barriers that have been overcome via on-line self-help are: lack of an existing local group–especially apt to be a problem in rural areas, provision of round the clock help rather than monthly help; overcoming transportation problems,

and support for shy persons or persons who are resistant to face-to-face meetings for other reasons (such as polio survivors who wish to "hide" limitations such as braces).

On-line sources of information can also reduce medical costs. On-line self-help can overcome problems of hierarchy because on-line self-help is less structured than traditional self-help groups–there is no formal leadership in on-line self-help. Indeed, on-line communication is an equalizer in that there are no visual distractions, i.e., signs of social status, age, dress, weight, race, appearance, and disabilities do not appear. On-line self-help groups can also effectively organize to provide feedback and suggestions for improving existing medical services and systems.

Expenses

Over half the organizations report newsletter and informational literature are reported to be the polio organizations' largest expense. Meetings and conferences are the next largest expense (see table 13).

Table 13: Major expenses for polio organizations

Major Expense	*Percent*	*N*
Newsletter/literature	52.1	37
Meetings/Conferences	18.3	13
Office expenses	11.3	8
Gifts/Awards	2.8	2
Other	15.5	11
Total	100.0	70

Table 14: Annual budget

Annual Budget	*Percent*	*N*
less than $500	50.7	39
$501-$1,000	13.0	10
$1,001-$5,000	20.8	16
$5,001-$10,000	5.2	4
$10,001-$20,000	3.9	3
over $20,000	6.5	5
Total	100.1	77

Half of the organizations have a budget of $500 or less (see table 14). Several wrote that they had no expenses. Some organizations reported meeting rooms and often meeting refreshments were provided for them. Some even had the printing and/or mailing of their newspapers provided by another organization.

While these organizations appear to be surviving with little financial support, for some there are expenses for printing and mailing newsletters and informational literature. While many are going to WEB sites for informational distribution, everyone does not have Internet access and there are frequently expenses for WEB sites.

Some organizations incur expenses for members attending conferences. Their own meetings might require fees for room rental, renting or buying videos, speaker expenses, or refreshments. When organizations give awards to recognize the support of individuals or other organizations, they can incur expenses for plaques and gifts. Some organizations are even large enough to maintain offices and a few have paid staff.

Where does the money come from?

The organizations raised money in a variety of ways including dues. Dues are minimal. Dues are $10 or less in over eighty percent (80%) of the organizations with half the organizations having no dues at all. The highest dues were $20 per year.

Over half receive donations some solicited directly from members and businesses. Nearly one in five (18.5%) report receiving a grant, eleven percent (11%) engage in fund-raising, and 7% charge for their newsletter (see table 15).

Table 15: Funding Sources

Dues/year	*Percent*	*N*
None	50.5	41
3.00	1.2	1
4.00	1.2	1
5.00	7.4	6
6.00	2.5	2
8.00	2.5	2
10.00	17.3	14
12.00	3.7	3
15.00	9.0	8
20.00	3.7	3
Total	100.0	81

Other sources of income	*Percent*	*N*
Donations	53.7	44
Grants	18.3	15
Fund raising	12.2	10
Newsletter	7.3	6
Other	15.9	13
Total	107.1	81

Totals are over 100% because some organizations used multiple funding sources

Member characteristics

As we would expect, this is an older population. Only about a third report any members below age forty (40). Only one organization had more than 10% in this age group. One in four organizations reports no members under fifty years of age. On the other hand, every organization reported having members in the fifty-one to sixty-five age group and all but one reported they had members in the sixty-six to seventy-nine age group. Over half reported members in their eighties or older.

No organization has more males than females. Female percentages ranged from fifty (50) to one hundred (100) percent with measures of centrality in the sixties - mean (67), median (65), mode (60). One in four organizations reported female percentages of seventy-five percent or greater. The female bias is in part reflective of the female bias found in older populations.

The organizations report their membership ranges from 75 to 100% Caucasian. Over two thirds of the organizations report white membership of 95% or above.

Characteristics of President / Coordinator

Table 16 reports the social and demographic characteristics of the organization's president or coordinator. We learned very quickly that some individuals and organizations considered our wording politically and organizationally incorrect. Specifically, several of the "support groups" have anti-hierarchal philosophies and structures that include coordinators but no president. In spite of our ignorance of this issue, most of the organizations provided us with information about their coordinator(s) even when they are not technically "presidents." For more thorough discussions of the self-help and support movements see Charleston (1998), Wollert (1999/2000), Gaston and Meissen (1999/2000), and Levin (1999/2000).

All but one of the presidents/coordinators were Caucasian, two of three were female, and their average age was sixty-one (61). These are reflective of the organization's membership. Two thirds of the presidents/coordinators were married at some time. Most reported past or present employment in the paid labor market. Three of four worked as professionals, semi-professionals, managers, or executives. For those we have information on, two-thirds hold a college degree and over eighty-five (85) percent have at least some college and everyone reported completing high school.

While the educational and occupational levels might appear high for a population of this age, the physical disabilities associated with polio likely ruled out employment in areas requiring sustained physical labor. Additionally, leaders frequently utilize communicative and management skills acquired in educational and white collar environments.

Table 16: Characteristics of President/Coordinator

Characteristic	*Percent*	*N*
Sex (N=76)		
Male	31.6	24
Female	68.4	52
Occupation (N=75)		
Professional	16.0	12
Semi-professional	42.7	32
Manager/executive	18.7	14
Clerical/sales	12.0	9
Skilled crafts	2.7	2
Operative	1.3	1
Never employed	5.3	4
Retired	1.3	1
Race (N=77)		
Asian	1.3	1
Caucasian	98.7	76
Marital Status (N=77)		
Married	64.9	50
Widowed	6.5	5
Divorced	11.7	9
Never Married	16.9	13
Education (N=72)		
High school	13.9	10
Associate/ Jr. College	23.6	17
Bachelors	31.9	23
Masters	22.2	16
Doctorate	8.3	6
Age		
Mean	60.7	
Range	39 - 88	

Leaders of polio organizations are similar to those found in other self-help groups. Medvene, Wituk and Luke (1999/2000) studied characteristics of leaders of a range of self-help groups. They reported the following demographic characteristics of the group leaders: 85% were female, 69% were married, 73% had some college education and 70% worked full or part time. Average age was 54. The relatively high rates for marriage and educational attainment are consistent with previous research on polio survivors (Bruno and Frick 1991; French and Sloss 1996).

What's in a name?

One way an organization presents an identity to the public is through its name. It is not surprising that most organizations included "polio" somewhere in the organization's name (see table 17 - left columns). Fully two of three used "post-polio," indicating the disease has passed even though most of these groups are clearly designed to help members deal with the after-affects of their disease and the possible onset of post-polio syndrome. One in six includes "survivor" in the name with one organization using "heroes" to refer to the members' struggles.

Organizations frequently include the type of organization in their name. Jerry Lewis's telethon that is primarily a fund-raising organization is a very different from a self-help organization even though both organizations might be organized about muscular dystrophy. Over half (56.6%) of the polio organizations included "support group" in their official name (see table 17 - center columns). Nearly twenty percent used "network," "association," or "connections."

A third way we classified organization names was to indicate who or what they were named after (see table 19). Four of five organizations include a geographic designation like the region, city, or state in which they are located (see table 17 - right columns).

Table 17: Type of Names

Polio reference	*Percent*	*N*	*Type of Org*	*Percent*	*N*	*Named after*	*Percent*	*N*
Post-polio	66.3	55	Support Group	56.6	47	Geographic	80.7	67
Survivor	18.1	15	Network	8.4	7	Person	2.4	2
Heroes	1.2	1	Other	14.5	12	Sponsor	4.8	4
Polio only	10.8	9	Association	8.4	7	Other	12.0	10
Other	3.6	3	Connection	2.4	2	Total	99.9	83
Total	100.0	83	None	9.6	8			
			Total	99.9	83			

Gender and Educational Differences in Leadership

The gender of the president/coordinator had no impact on organizational characteristics. There were no statistical differences in the type of organization (e.g., support group, network), wether the organization had non-profit status or a mission statement, affiliations with hospitals, clinics or other polio organizations, or whether the organization had an e-mail address or WEB site. There were no differences in the size of membership, meeting attendance, time or day or meetings, who plans the meetings, meeting activities (e.g., speakers, sharing experiences), amount of dues or size of budget, newsletter characteristics, average age of members or even the sex of members.

With a few exceptions, a similar lack of a pattern emerged for educational characteristics of the president/coordinator. Organizations headed by individuals with less education were more likely to have non-profit status and be associated with polio clinics. However, those headed by individuals with an associate/junior college or PhD degree were more likely to have a mission statement. Organizations headed individuals with high school diplomas were most likely to have an e-mail address (80%) but least likely to have a WEB site (20%). Organizations with the highest frequencies of WEB sites were headed by individuals with an associate/junior college degree (53%) or a PhD (83%).

Differences by Type of Organization

The sample was divided into two types of organizations - support groups and networks. Organizations with "support" in their names were put in one group (N=47) while those with network, association, or connection were another group (N=16). Bivariate analysis revealed several differences between the two groups. On average, the networks were larger than the support groups with a mean size of 430 compared to 158 and with larger meeting attendances of 34 compared to 19 While still minimal, networks on average charged more for dues ($8 vs. $4). Networks were also more likely to report non-profit status (73% vs. 31%) and were more likely to have a WEB site (56% vs. 19%).

Networks were more likely to publish a newsletter and a support group (94% vs. 66%). Of those that printed a newsletter, it is not surprising that the networks, who had more members, printed on average more newsletters than support groups (587 vs. 268). The newsletters from networks also had on average more pages (9.2 vs. 7.0) but fewer issues per years (5.5 vs 7.4).

The two types of organizations did not differ in the demographic characteristics of their presidents/coordinators, sex or age of members, affiliations with hospitals, clinics, or other polio organizations, having mission statements, or time of meetings. Even the meeting activities were very similar.

Effects of Size

As noted above networks were larger than support groups and had more members attend meetings. However, as membership size grows, the ratio of members who attend meetings declines. The number who attend meetings does have some impact on the nature of the meetings. While meeting size is not related to sharing experiences, social gatherings, or working to change laws and policies, larger meetings are positively related to films and speakers on medical issues, technologies for assisted living, and social service benefits.

Summary and Conclusions

This paper reports on a sample of eighty-three (83) polio organizations from English-speaking nations, the majority (74) from the United States. The organizations were founded between the years of 1939 and 2001 with most founded in the middle 1980s. The size of the organizations ranged from seven (7) to nine thousand (9000) which a median size of about 100. Most members were white, female, and between the ages of fifty-one and seventy-nine. Meeting attendance, on average, ranged from four (4) to one hundred ten (110) with a mean of twenty-five (25) and median of eighteen (18). The most popular meeting activities were medical speakers.

Most organizations operated on minimal budgets and charged no or minimal dues. Many were associated with other health care organizations (e.g., hospitals, clinics) and with other polio organizations. These affiliations often proved meeting space, speakers, and financial support either directly or indirectly (e.g., print and mail newsletters).

Bivariate analysis finds no organizational differences related to the gender of the president/coordinator and few differences by the leaders' educational background. Support groups were smaller than networks but other differences were minimal. The size of the polio organization was related to some types of meeting activities but other differences were minimal.

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