

**InterGroup Services
Client Report**

**An Assessment
of the Needs of
Buddy/Companion
Program Clients
in Central
Maryland**

Client: Baltimore City Health Department

Project: Needs Assessment of Buddy Program Clients

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1. EXECUTIVE SUMMARY

InterGroup Services, Inc. (IGS), a Baltimore-based, project-management firm, was in late 2002 contracted by the Baltimore City Health Department to conduct an explorative study, determining client expectations with regard to buddy/companion programs for HIV- or AIDS-infected persons in the area. The findings of this study will be used for planning by the Greater Baltimore HIV Health Services Planning Council. Buddy/companion programs connect people living with HIV/AIDS (PLWH/As) with volunteer “buddies” to provide them with companionship and assistance with various services. These services run the gamut from household assistance, to transportation, to emotional support. Buddy/companion programs have existed in central Maryland since the mid-1980s.

There are two federally funded buddy programs in the region. The HIV/AIDS Volunteer Enrichment Network (HAVEN) provides buddy services to residents in Anne Arundel County and the surrounding areas. Buddy services in Baltimore City are coordinated through the Health Education Resource Organization (HERO).

IGS devised a survey to be delivered to PLWH/As through two organizations: (a) Moveable Feast and (b) the Greater Baltimore HIV Health Services Planning Council or, more specifically, its PLWH/A Committee. Moveable Feast is an organization that delivers groceries and meals to people living with HIV who have varying degrees of mobility. For its part, the planning council directs the allocation of Ryan White CARE Act, Title I funds for the area. Moveable Feast delivered 200 questionnaires to its grocery recipients and another 40 to its cooked-meal recipients. A further 100 surveys were distributed by the planning council PLWH/A Committee’s members to various of their associates and acquaintances.

Each survey packet contained: a letter from the planning council chair, the questionnaire and a stamped envelope, addressed back to InterGroup Services. Twenty surveys were returned from Moveable Feast’s grocery-delivery group, one from its meal-delivery roster and twelve from among the PLWH/A Committee-distribution recipients. There were 33 respondents in total.

Most of the respondents (28) did not have a buddy. There were five respondents that currently had a buddy. “Companionship” was most popular response when the participants were asked to describe the services that they would like to see a buddy provide. “Transportation” was the second most popular response. Help with final-stage support came next, acknowledged as important by 12 of 33 respondents. Help with “talking to providers” was important for a similar number of respondents, 11.

In terms of what they would like their buddies to be *like*, most survey respondents indicated that they would prefer it if their buddies (a) had personal experience with HIV (18 of 33 respondents), (b) shared interests with them (16), and (c) approximately matched their age (12). Matches on sexual preference (10), race (9), gender (8), religion (6) and place of residence (5) were less important.

— InterGroup Services, Inc.

2. PROGRAM BEGINNINGS

This background is an effort to explore the history of buddy programs in central Maryland as funded through the Ryan White Comprehensive AIDS Resources Emergency Act of 1990 (usually simply known as the CARE Act) and its reauthorizations, the challenges such programs face and how the sponsoring agencies have met those challenges.

It is not clear where or when the buddy concept in relation to HIV services originated. However, the general concept of volunteers providing aid to the sick and easing the discomfort of the disabled has, within the last century and a half, helped form the foundation of what are now professional fields in their own rights, such as social work and nursing. For example, many of the women who followed Florence Nightingale to the British military hospitals in Scutari, Turkey during the Crimean War (1854-56) were simply charitably motivated volunteers, despite the professionalism accorded them by their association with Nightingale, the founder of modern military nursing. Though Nightingale and her immediate entourage were paid, many others were not. Like Nightingale, they had responded in droves to the clarion call of the London *Times* for “sisters of charity” to go to the aid of the wounded after such bloodbaths as the battles of the Alma, Inkerman and Balaclava (Woodham-Smith 1951:85).



Explorer David Livingstone: an early buddy model, combining medical with missionary care.

Coordination of volunteers to ease the suffering of those who are ill continues to be a service found within the missionary arms of various religious institutions today. Indeed, even during the heyday of Victorian Christian missionary activity in Asia and Africa, much disparaged today, applicants to missionary societies were given an especially warm welcome if they combined medical knowledge with their evangelical zeal. Among no one was this combination more apparent than the most famous missionary of the 19th century: David Livingstone. When journalist Henry M. Stanley (*né* John Rowland) addressed Livingstone in 1871 on the shores of Lake Tanganyika with the immortal line, “Dr. Livingstone, I presume,” he was addressing the latter as a medical doctor as well as a religious minister (Ferguson 2002:126, 160).

Despite the cloudy beginnings of HIV buddy services, we do know that there were myriad buddy programs aimed at helping people with HIV or AIDS beginning in the 1980s in major cities across the country and in Canada (ACCM 2003; APLA 2003; Weber 2000). In the 1980s, buddies provided a vast array of services to the clients. Each buddy did everything from taking a client to the hospital, to performing chores, to negotiating with care providers, to bedside care. These programs were set up so that each buddy volunteer provided a host of services for a single client, in addition to general companionship and final-stage support. (Final-stage support runs the gamut from emotional support, to more tangible end-of-life preparations like the assignment of guardianship for minor children and funeral arrangements.) It should be little wonder that the traditional role of buddy volunteers encompassed all of these tasks during a decade which saw a dramatic increase in deaths attributed to the AIDS epidemic and a service-delivery system that was struggling to identify and meet the service needs of people dying of the disease. As we shall see, the fact that HIV/AIDS is no longer necessarily the mortal affliction it once was has changed buddy programs.

2.1. Buddy Programs in Central Maryland

As defined by the U.S. Health Resources and Services Administration (HRSA), buddy/companion services are “activities provided by peers or volunteers to assist a client in performing household or personal tasks, Buddies also provide mental health and social support to combat loneliness and isolation” (HRSA 2002:107). This has essentially been the case for some years though, as we shall see in the case of the two programs described below, there has of late been a shift in emphasis (a) toward peer-provided companionship (as opposed to companionship provided by run-of-the-mill volunteers) and (b) toward a division of labor, with each buddy providing one segment of service to a number of clients, as opposed to being a general *factotum* for one person.

In 1983, health practitioners at the Johns Hopkins Hospital began to see the first cases of HIV and AIDS in the Baltimore area (Kotval 2003). Out of concern for the social needs of these patients, beyond the scope of medical care, these practitioners looked to the Health Education Resource Organization, Inc. (HERO) to provide social services and case management to people with the disease. Initially, these services included legal assistance, case management and buddy companionship, says Indira Kotval, HERO’s deputy executive director (Kotval 2003).

Through the years, HERO’s buddy/companion program has undergone some changes. In 1987, HERO petitioned the Maryland Department of Infectious Diseases, within the Maryland Department of Health and Mental Hygiene (and out of which was born the Maryland AIDS Administration), for funding for people with AIDS. HERO was awarded a lump sum of \$125,000 for patient services. The money was to be used to supply each infected client with a case manager, a part-time lawyer and a “buddy.” HERO received funds from this source until the early 1990s.

By the late 1980s, there were stirrings to get buddy programs instituted in the Baltimore suburban counties as well as the city. In 1989, after training as buddy volunteers at HERO, two Anne Arundel County participants saw the need to have similar services available for county residents. Out of this was born the HIV/AIDS Volunteer Enrichment Network (HAVEN), incorporated in 1992. HAVEN’s buddy program is currently funded through Title I of the CARE Act, Maryland state government funds, and corporate and private donations (HAVEN 2003).

With the introduction of funding by means of the CARE Act in 1990, and the local implementation of CARE Act Titles I and II, moneys within central Maryland were available by 1992 for buddy programs in the area. The planning bodies for CARE Act funds in Maryland began to identify buddy/companion services as a service priority for people living with HIV/AIDS. State funds for the buddy program under HERO targeting Baltimore City residents were replaced, in the early 1990s, with CARE Act Title II funds that to this day are distributed by the AIDS Administration. By the mid-1990s, the Title I planning body, the aforementioned Greater Baltimore HIV Health Services Planning Council, supplemented Title II funding in the area by allocating Title I funding to provide buddy services in the counties of Anne Arundel, Baltimore, Carroll, Harford, Howard and Queen Anne’s. HAVEN’s program is thus funded under Title I.

2.2. Program Evolution

Two local organizations have funded buddy programs under Titles I and II — HERO and HAVEN. The HERO and HAVEN buddy programs have both moved beyond providing buddy services in the old, traditional sense, i.e., one client, one buddy. What is of particular interest here

is that each has formulated new practices by which the experiences of both the client and volunteer can be enhanced. This change has been due, in part, to the small number of buddy volunteers compared to the growing size of the HIV/AIDS population. Additionally, with the advent of more education regarding modes of transmission, infected individuals may not be as isolated from their social-support networks as they were in the beginning of the epidemic. Finally, 20 years into the epidemic, the service-delivery system available to HIV-positive clients today is more varied and complex to better address the multiplicity of needs of the community affected by the epidemic.

The HERO program in Baltimore City has been revamped by utilizing a two-tiered model. The first level of the model pairs relatively healthy clients with newly diagnosed clients (Kotval 2003). It is assumed that, in this way, the newly diagnosed will be taught how to navigate through services by their more experienced peers, thereby creating and maintaining a stronger link to the health- and social-care system. The second tier of the model involves community involvement in the care of those clients with severely impaired health. HERO recruits organizational members from a local group called Churches United Against AIDS to offer one-on-one to support clients that are very sick (Kotval 2003).

HAVEN, in Anne Arundel County, has chosen a different approach for dealing with the increasing need for volunteer buddies and the changing expectations of both buddy and client. At HAVEN, the buddy program has changed its focus from intensive, multifaceted services on an individual level (that is, from the traditional buddy approach) to multi-provider, social support focusing primarily on companionship. HAVEN has focused on building a community within which there is a network of volunteer support services that an individual client can call upon. Whereas, previously, a buddy volunteer could expect to provide an array of services to a single client, now there is something of a division of labor, with each buddy specializing in the provision of a particular facet of the overall service package to a number of clients.

HAVEN has a buddy coordinator — the entry point for someone coming into service. Once a client accesses the “service community” for the first time, the coordinator arranges for that person to have one-on-one interaction for the first couple of months. During this time, the client is gradually weaned off of this one-on-one interaction (although a level of this is maintained), while simultaneously becoming more integrated into the service community. Within this community, the responsibility for one person’s care is transferred to the collective, that is, to a number of volunteers, each providing a particular service. This helps to reduce volunteer burnout and client isolation, if only because clients get to meet more buddies this way. Additionally, the transfer from individual support to community support helps to identify and fill the gaps created by a buddy relationship solely between two individuals. Volunteers may spend their time providing just one service, but to many clients. For example, some volunteers may spend three days out the week transporting different clients to their various destinations.

HAVEN has employed several mechanisms to maintain contact with both its clients and volunteers. HAVEN offers support groups and, for those who do not wish to attend support groups, there are social gatherings once a month. Volunteers and clients are invited to these events. In addition to these gatherings, there are four annual events that include families, as well. The ultimate goal of this model is to get the person involved in a mutually supportive community of volunteers and people living with AIDS.

3. CHALLENGES TO BUDDY/COMPANION PROGRAMS

This section covers the challenges observed by or facing current providers of buddy/companion services. It also highlights the degree to which current providers continue to improve their programs to meet the needs of new clients coming into care.

3.1. Communities Affected by the Epidemic Today

Along with the evolution of society's knowledge about HIV and AIDS came a significant change in the populations affected by it. The AIDS epidemic was initially associated largely with white, gay men. Accordingly, a great number of volunteers for buddy programs were drawn from this population subgroup. These volunteers provided support for their peers who were marginalized from the larger population because of their sexual orientation and disease status (Goforth 2003).

With the progression of the AIDS epidemic over the past two decades, the demography of the infected population, particularly of the newly infected, has changed. What was once in good measure a disease of white, gay men, had by the turn of the 21st century become a disproportionately African-American epidemic. In Maryland, in 1986, African-Americans accounted for 51.9 percent of new diagnoses; whites, for 43.8 percent. By 2001, black Marylanders constituted 83.5 percent of the pool of newly diagnosed persons, while whites comprised 14.2 percent (DHMH 2002:64). In 2000, the overall population of the state was 27.9 percent African-American (DOP 2001).

With the advent of highly active anti-retroviral treatment (HAART), fewer HIV-positive people are dying and fewer are being diagnosed as AIDS defined. This means more people need services in order to live with and manage HIV and AIDS. Newly diagnosed clients often enter programs with a multiplicity of needs exacerbated by co-morbid factors such as homelessness, drug use, mental illness and hepatitis C.

With regard to buddy/companion programs, this change has prompted an emphasis for a more diverse set of volunteers to meet the varying needs of new clients. As the epidemic increasingly came to include African-American substance abusers, professional women became the new wave of buddy volunteers (Goforth 2003). The AIDS epidemic has outpaced the volunteer body and, as a result, each organization has been trying to increase the pool of buddy volunteers.

3.2. Volunteer Recruitment

Recent strides in HIV/AIDS medication have created a challenge for HERO and HAVEN. With the development of HAART, there has been a shift in the general perception of HIV and AIDS. People's understanding of the disease has not kept pace with the increasing complexity of the disease. What used to be thought of as a terminal illness is now conceived of as a chronic illness that can be effectively controlled with the proper medications. Consequently, there has been a shift in the perception of urgency by which potential volunteers assess the need for their services.

3.3. Buddy Accountability

Buddy accountability is a challenge, according to HERO. Because the buddies are unpaid volunteers, supervisors must avoid the appearance of being too strict in terms of time and too restrictive in terms of activities. As a solution, there have been talks about offering buddy

volunteers a stipend (Kotval 2003). In this manner, because of the exchange of money, the agency would have more license to obtain a record of activity from each buddy. It is unclear whether or not such stipends will be instituted for buddies. What is clear is that there is an organizational effort (a) to examine current issues with the program and (b) to propose ways of maximizing the buddy experience for both volunteer and client.

HERO's and HAVEN's buddy programs have gone through some transition. New advances in the treatment of HIV and AIDS have prompted some of these changes. The perceptions of volunteers and the level of energy that they are willing to commit to the buddy role is also a factor. Officials at both HERO and HAVEN have striven to find ways to meet the changing expectations of volunteers and clients. They are adopting innovative strategies to meet these challenges and to effectively meet the needs of people living with HIV and AIDS.

It is important to examine the challenges that both HERO and HAVEN face with regard to their buddy programs. Each organization has reviewed the pitfalls it has noticed in the program and each has striven to meet the challenges faced. Their ability to devise ways of improving the programs is demonstrative of their commitment to the infected/affected community. The remainder of this evaluation focuses on the data collected from HIV-positive individuals regarding their perception and expectation of buddy programs.

4. SURVEY METHODOLOGY

This section describes the methods used by IGS to gather the data used for this study. The subsequent section describes the actual findings.

4.1. Assessment Tool

The assessment tool was developed based on the Title I planning council's premise that funding allocation for programs should be guided by the current needs of people living with HIV and AIDS. Because of the current epidemiological profile of people living with HIV and AIDS in central Maryland, the length of the tool was limited to one page to make it easier for those who are more severely ill to respond to the questionnaire. Questions on client demographics and profiles were not included, in order to keep the survey short for respondents. The survey was comprised of six questions targeting the participants' history with buddy programs and their expectations of buddy companions (a copy of this questionnaire can be found at appendix 1).

The first two questions were related, and asked specifically about a respondent's activities in trying to get a buddy. For the second two questions, survey participants were allowed to indicate all of the categories that applied (in other words, "check all that apply" rather than "check one"). These two questions made inquiries about the services that were expected from a buddy and the preferred buddy characteristics.

The last two questions were open-ended and required the respondents explicitly to indicate the time commitment they expected of a buddy, both weekly and in total. These were open-response questions, so that the nuances of time expectations on the part of the clients could be captured.

4.2. Distribution

IGS determined that the best means of distributing the survey to would-be respondents was through convenience sampling, enlisting the assistance of groups known to be in close and regular contact with AIDS-infected persons. Convenience sampling allowed for the greatest flexibility in recruiting participants at varying stages of the disease progression, with the assumption that individuals in varying stages of illness might have differing expectations or requests of volunteers assigned to them.

4.2.1. Moveable Feast

Formerly called the Maryland Community Kitchen, Moveable Feast is a program that offers free meals to homebound AIDS patients and grocery-delivery services to more mobile clients (CUCC 2003). Moveable Feast delivers groceries to 200 clients and delivers prepared meals to another 40, according to Nancy Guest, a coordinator for the program (Guest 2003). Moveable Feast was solicited as a distribution partner because its current food-delivery contract under Ryan White, Title I requires that it make a determination of service need for home-delivered food based on the health condition of each client being served. Moveable Feast provides an initial assessment at intake on the client's nutritional needs based on the each client's current medical condition and health status. For those clients with limited mobility, groceries are delivered to the clients' homes. For those who are not only homebound but have difficulty preparing meals in their own homes, cooked meals are provided on a regular basis.

Two hundred forty surveys were distributed to clients by Moveable Feast on behalf of InterGroup Services for the purposes of this study. The surveys were color coded to distinguish the responses of the grocery-delivery clients from those of the more severely ill meal-delivery clients. Apart from the color difference, there were no identifying characteristics on the forms. No identifying material was solicited from respondents. The surveys were distributed in a package including a letter describing the purpose of the survey and a stamped envelope addressed to InterGroup Services. (The explanatory letter may be reviewed at appendix 2.) All responses were entirely anonymous.

4.2.2. PLWH/A Committee

The PLWH/A Committee is a standing committee of the Greater Baltimore HIV Health Services Planning Council. “PLWH/A” stands for “people living with HIV/AIDS.” The planning council is a 40-member body appointed by the mayor of Baltimore City to plan funding-related matters for HIV services in the Baltimore metropolitan area. It is charged with directing CARE Act Title I dollars to most effectively meet the needs of the area’s HIV-infected population. Of the planning council’s various standing committees, the PLWH/A Committee is charged with advocating for the needs and rights of the infected/affected community (PC 2003). The PLWH/A Committee is also responsible for assisting with the identification of target locations and populations for needs-assessment purposes.

Members of this committee were instrumental in distributing the surveys to other PLWH/As. The premise for solicitation of respondents through the committee was to target respondents successfully managing their disease but perhaps still in need of the support services of a volunteer buddy. One hundred surveys were distributed in this manner. Combined with the Moveable Feast surveys, the total number distributed in one way or another was 340.

5. RESULTS

Of 340 surveys distributed in total, 33 were completed a returned to IGS by the cut-off date, a response rate of 9.7 percent. Of the 240 surveys distributed to Moveable Feast, 200 were given to those participants having groceries delivered to their homes. Another 40 were allocated for clients receiving home-delivered meals. Of the 200 delivered to Moveable Feast’s grocery-delivery clients, 20 were completed and returned (10 percent). Of the 40 going to the meal-delivery clients, only one was (2.5 percent). As for the 100 questionnaires distributed by members of the planning council’s PLWH/A Committee, 12 were filled in and returned to IGS (12 percent).

In total, 7 respondents had applied for a buddy at one point or another; 26 had not. Among the seven that had applied, a plurality (3) had done so recently, in 2002. With the exception of one, none of Moveable Feast’s grocery-delivery participants (GDPs) had ever applied for a buddy. Six of the PLWH/A Committee distribution respondents (PCRs) said that they had applied to receive a buddy, and five indicated actually having a buddy now. The one Moveable Feast meal-program respondent (MPR) said that he or she had not applied for a buddy.

5.1. Preferred Buddy Support

As for the types of support that consumers would like to receive from a buddy (table 1), companionship (10, 12 and 1 respondents) and transportation (7, 8 and 1) were the highest ranked among the grocery-delivery, committee-distribution and meal-delivery groups, respectively. Other types of support noted as being important by the GDPs included: final-stage support (6 respondents), housekeeping (4), assistance in talking to providers (4), meal preparation (3), running errands (2), and assistance in talking to family and loved ones (2). The PCRs saw the importance of: running errands (7), assistance in talking to providers (7), and assistance in talking to family and loved ones (7) as the greatest needs, after companionship (12) and transportation (8). Five PCR participants indicated that they would appreciate final-stage support from a buddy. Housekeeping and meal preparation both had four PCR responses. There were two marks for the “other” category for this question, both from PCRs. When prompted to expand on what these other services might be, the respondents replied that they would like child-care services and someone to just check in to see how they were doing.

Table 1 Preferred Buddy Support	GDP N=20	PCR N=12	MPR N=1	All N=33
<i>You want these services from your buddy:</i>				
Companionship	10	12	1	23
Transportation	7	8	1	16
Run errands	2	7	0	9
Meal preparation	3	4	0	7
Housekeeping	4	4	0	8
Final-stage support	6	5	1	12
Help me talk to providers	4	7	0	11
Help me talk to family and loved ones	2	7	0	9
Other	0	2	0	2
Total	38	56	3	97

Table 2 Preferred Buddy Characteristics	GDP N=20	PCR N=12	MPR N=1	All N=33
<i>It is important that your buddy:</i>				
Match your age	6	6	0	12
Match your race	4	5	0	9
Match your religion	3	3	0	6
Match your gender	4	4	0	8
Match your interests	6	10	0	16
Match your sexual preference	6	4	0	10
Live or work in your neighborhood	3	2	0	5
Have personal experience with HIV	11	7	0	18
Other: faithful	0	1	0	1
Other: respectful	0	1	0	1
Other: unbiased	0	1	0	1
Other: open personality	0	1	0	1
Total	43	45	0	88

In addition to being asked if transportation would be a service expected from the buddies, in some cases respondents indicated the frequency and type of transportation that they would like to see offered. Six of the 16 responses to this question indicated that they would like transportation provided one to five days a week. Two respondents indicated that transportation would be needed once or twice a month. Although the questionnaire did not explicitly inquire about the purpose of the transportation, some of the respondents volunteered the information. Most of the responses in this category called for transportation to doctor’s appointments and office visits. Others mentioned running errands, picking up medications and shopping.

When asked about the type or frequency of errands that clients would appreciate assistance with from a buddy, many of the answers were similar to those from the previous question. In addition to those mentioned above, participants noted that they would like help with mailing bills and going to the post office. Housekeeping tasks mentioned were: cleaning floors, doing laundry, vacuuming, cooking and general cleaning.

5.2. Preferred Buddy Characteristics

Participants in this survey were asked to indicate the characteristics where it was important that they and their buddy be matched. The responses are shown in table 2. Most grocery-services respondents listed “personal experience with HIV” as their top choice (11). This category was the second most important category (7) for the committee-distribution respondents though, for most of this PCR group, having a buddy with similar interests (10) was most important. The sole respondent from the meal-delivery group did not respond to the questions in this section.

Considerations of race (4 and 5) and age (6 and 6) seemed to hold slightly lesser value when matching a client to a volunteer. Equal numbers of both the grocery-delivery and the committee-distribution respondents indicated that they would like the buddy to be close to their age (4), be of the same gender (4) and be of the same religion (3).

Table 3 Preferred Weekly Time Commitment	GDP N=20	PCR N=12	MPR N=1	All N=33
<i>Your prefer this many hours a week:</i>				
1 hour	1	0	0	1
2 hours	3	1	0	4
3 hours	0	2	0	2
4 hours	1	0	0	1
5 hours	1	3	0	4
10 hours	2	0	0	2
15 hours	1	0	0	1
16 hours	0	1	0	1
3 days	1	1	0	2
Only when needed	2	3	1	6
Don't know	0	1	0	1
No response	7	0	0	7
Total	19	12	1	32

More of the grocery-delivery respondents than committee-distribution respondents indicated that they would like their buddy to be of the same sexual preference (6 and 4, respectively). By their low responses, both groups implied that it was not particularly important that their buddies live or work in their neighborhood (3, grocery delivery; and 2, committee distribution).

The PCR group was the only group to have responses to the “other” category for this question (4). Being “faithful,” “respectful,” “unbiased” and having an “open personality” were the elaborating responses.

5.3. Preferred Weekly Time Commitment

Consumers were asked to specify how many hours they expected a buddy to spend with them during the week. This was an open-response question. The responses are shown in table 3. The plurality of both the grocery-delivery and the committee-distribution groups expected their buddies to be available to them between one and five hours a week (6 and 6 responses). Three GDPs and one PCR indicated that a buddy should be there for them between 10 and 16 hours per week, inclusive. One respondent from the grocery-delivery group and one from the committee-distribution group stated that the buddy should be there for them three days out of the week. Two grocery-delivery and three committee-distribution respondents, along with the one meal-delivery participant, said that their buddy should be there only when needed. Seven GDPs did not respond to this question.

5.4. Preferred Cumulative Time Commitment

Each survey asked the consumers to indicate how long they would expect a buddy to be there for them in total. The responses are tabulated at table 4. Two grocery-delivery respondents stated that the buddy should be there for three months, one respondent stated six months and four respondents said 12 months. Two PCRs said 12 months, one said 5 months and one said 24 months. Seven grocery-delivery respondents, six committee respondents and the meal-delivery

Table 4 Preferred Cumulative Time Commitment	GDP N=20	PCR N=12	MPR N=1	All N=33
<i>Your expect this cumulative time:</i>				
3 months	2	0	0	2
5 months	0	1	0	1
6 months	1	0	0	1
12 months	4	2	0	6
24 months	0	1	0	1
Other: once a week	3	0	0	3
Other: at end of life	1	0	0	1
Other: when needed	2	0	1	3
Other: once a month	1	0	0	1
Other: every other month	0	1	0	1
Other: as long as buddy is comfortable	0	1	0	1
Other: uncertain, health is fine, I have other support	0	1	0	1
Other: until I can do for myself	0	2	0	2
Other: until mutual closure	0	1	0	1
No response	5	0	0	5
Don't know	0	2	0	2
Total	19	12	1	32

respondent gave answers that, while of note, were not quantifiable within the parameters of the question. These responses included: once a week, until the end of life, when needed, once a month, every other month and “until mutual closure is reached.” Five grocery-delivery participants did not respond to this question. Two committee-distribution respondents indicated that they did not know how long they expected a buddy to be there for them.

6. DISCUSSION

The purpose of any data analysis is to find salient ways of transforming raw data into useful information. This analysis is no different. In this section, trends, response rates and data anomalies are investigated in conjunction with an understanding of the context in which these data were collected.

There was no identifying information solicited from any of the participants in this survey, so what little IGS knows of the participants is inferred by having targeted clients at various stages of their illness through the distribution methodology. IGS believes, though cannot be certain, that all the respondents were from the Baltimore area. Additionally, there were no mechanisms put in place to make the committee distribution exclusive from the other two, though the overlap is thought to be minimal.

With respect to the three groups, it is assumed here that the grocery-delivery and meal-delivery participants are further along in the disease progression than those participants from the committee-distribution group. This assumption is based on the standard medical requirements for enrollment in the sort community-kitchen program in which the grocery- and meal-delivery participants were enrolled. As for the other group, there is higher probability that newly diagnosed and/or asymptomatic people living with HIV are included in the committee-distribution group than in either of the other two. In conjunction with the aforementioned screening process, it is assumed here that there is a higher level of mobility among the committee-distribution participants than among the grocery-delivery and meal-delivery participants. Not having signed up for any food-related service, the PCRs are assumed to be well enough not to need such services. With these points in mind, the patterns, trends and anomalies are examined below.

6.1. Needed Buddy Services

“Companionship” is obviously an important issue, with each of the groups rating it highest among the list of services to be rendered by potential buddies. This may speak to a level of isolation felt by the consumers despite their level of integration into the HIV/AIDS care system.

If it is true that the grocery- and meal-delivery participants are more integrated into the system of care, then it follows that their need for a buddy to run errands, as indicated by the response rates, should be lower than those participants in the committee-distribution group. This seems borne out by the responses: 7 of 12 PCR responses gave errands as an important buddy function, as against only 2 of 20 GDP answers. The one MPR did not think it important either. There proved to be a similar pattern among the responses given for “assistance in talking to family and loved ones”: the MPR did not mention it, and only two GDP responses did, as against seven PCR answers. The pattern for the question about talking to providers was similar, though not as pronounced: seven PCR responses, compared to four GDP responses (the MPR was silent on the issue). PCRs may be less integrated into a social-support network that can assist them in these activities and therefore may be more inhibited in their interactions with care providers, family and friends concerning their disease status, hence their greater emphasis on needing assistance in this matter from buddies.

Each group reported final-stage support as a service needed from a buddy: six GDP responses, five PCR responses and the one MPR. This may be indicative of a current gap in services or condition of unmet need with regard to end-of-life preparation among this population.

6.2. Buddy/Client Compatibility

The highest-rated match characteristic among each of the groups was the matching of clients with buddies having personal experience with HIV. Clients in the grocery-delivery system may particularly value this characteristic because they may be further advanced in their disease than the PCRs and therefore may need to have volunteers who can relate to their current health status and experiences. On the other hand, the sole meal-delivery respondent did not think this an important characteristic and, typically, Moveable Feast's meal clients have more advanced symptoms than the grocery clients. Regardless, in general, the Moveable Feast participants may also need someone who can offer disease-specific information. Personal experience may also be important in that buddies with such experience may be more apt to spot inconsistencies in care and client condition. Committee-distribution participants may view a buddy's personal experience with HIV as a tool to be used in assisting the client to navigate through the care system. It also may be important in the creation of a supportive resource network for the client. Both groups may find a match with a buddy who has personal experience with HIV as being likely to foster a relationship based on empathy and producing motivation. The personal experience may also provide the foundation from which a mutually beneficial relationship between client and buddy can be based.

Having similar interests with the consumer is another characteristic that respondents felt to be important in the matching process. With six responses, this was the (equal) second most cited answer for the GDP group. For the PCRs, with 10 responses, this was the most important buddy characteristic. Both groups have a level of mobility, perhaps allowing them to explore their interests. Maintaining as much normality as possible, despite living with HIV, is a crucial element ensuring a quality of life. Again, it also provides a common ground upon which to build a client/buddy relationship. By contrast, Moveable Feast's meal clients are more likely to be housebound.

Sexual preference scored relatively high among grocery-delivery respondents (6 of 20). The proportion of responses in this category was the same for committee-distribution participants (4 of 12). Matching on religion (3 and 3) and gender (4 and 4) appeared to be somewhat less important for both the grocery-delivery and committee-distribution groups, respectively, while race (4 and 5) and age (6 and 6) seemed to hold greater value. Matching on demographic characteristics may increase client comfort, but the importance of this seems to be overshadowed by other considerations (experience and interests, in particular).

6.3. Buddy Commitment

There was a great variation among the responses to the questions about buddies' weekly and cumulative time commitment. There are no apparent trends or patterns among groups in response to these issues, particularly in regard to weekly commitment. Perhaps more needs to be done (a) to get a more complete picture of clients' expectations with regards to buddy commitment and (b) to ensure that both buddy service providers and clients have a realistic understanding of the necessary level of volunteer commitment. While they may in the aggregate have had a somewhat confused idea as to how many hours per week a buddy should stay with them, the respondents were fairly clear that, in the larger picture, they wanted a long-term commitment from a buddy. A plurality (6) said their buddies should be with them for a year. This need for large-scale volunteer time may also be indicative of their need for more constant companionship.

7. LIMITATIONS

There are some important limitations to this analysis. Readers should bear this in mind before drawing conclusions. Most important is the small size of the respondent pool, only 33. Mail-back surveys commonly produce a low rate of return. This study's response rate of nearly 10 percent is actually relatively high. Unfortunately, the total survey pool was small to begin with, only 340 people. While the mail-back method used by IGS may be said to have resulted in a small data set, there was no other way of distributing the surveys while yet maintaining client anonymity — the latter a crucial consideration. Ensuring the protection of identity for this population is vital, considering the level of stigma associated with being infected by this disease. The other minor limitation is that not every respondent answered every question. With mail-in surveys, there is no way around this problem.

Given the small number of respondents, what IGS has gathered is essentially a qualitative data set. The collection of qualitative data produces results that are not generalizable. There were 33 participants in this study. This number is far too small to provide statistical significance. What the information presented here provides is valuable qualitative data that should prove helpful in the evaluation and planning of buddy/companion programs.

8. CONCLUSION

Despite growing societal knowledge about HIV/AIDS, there is still a great deal of social isolation that infected persons endure. Additionally, as the rate of infection is still alarming, there is a definite need for more programs that will assist infected individuals in coping with the disease and living in spite of it.

The nature of buddy programs has evolved as a result of client needs. The analysis of the original data given above, combined with the history of programs in the greater Baltimore area, illustrate client needs and the efforts of federally funded programs to meet those needs. In addition to the isolation that occurs with decreased mobility as the disease progresses, there is also the isolation caused by social stigma. Given this, it is not surprising that, above all else, the data show that there is a felt need for companionship among this population.

8.1. Planning Implications

These qualitative data results support planning efforts that emphasize appropriate initial assessment of a client's needs for buddy volunteers, with sensitivity toward (a) the client's desired array of buddy services and (b) the characteristics the client wants in a buddy. Emphasis on expanding initial client assessments to evaluate the client's need for companionship versus the client's needs for specific aid (e.g., providing transportation, running errands, etc.) may be a valid consideration for planners.

Planners should take into consideration that a number of the respondents still do view buddy volunteers as important support in providing final-stage support, a role that buddies have historically played since the 1980s. As this study was not able to solicit responses from those clients nearing the end stage of the disease, an exploration of the needs of those in palliative care or those severely disabled related to social support merits study.

8.2. Current Developments Vindicated

The report's questionnaire responses seem also to support the direction that HERO and HAVEN have begun to take in recent years. HERO's mentorship-style buddy program provides a critical service that can quickly address the client's need for companionship and to connect with someone with experience with HIV. Encouragement of HAVEN's approach of volunteers providing specific tasks for a number of clients (such as transportation) may also address the client's needs for specific aid, such as transportation, while maximizing the time volunteers are willing to dedicate to the program. Readers should recall that a plurality of respondents (12) considered that buddy volunteers should be with them for a year.

Since the emphasis of this study is to provide the Title I planning council with information on the needs of PLWH/As, this study did not explore the perception of volunteers related to commitment to a program. Planning and implementation of programs should take into consideration the buddies' expectations when first stepping forward to volunteer their services.

An additional consideration for planning is for better coordination of buddy services with services that have been formalized and expanded within the last few years. Unlike the buddy services that were created early in the epidemic to address the gaps in social-support services available to consumers, programs such as client advocacy and non-traditional outreach have been developed within the last five years specifically to address the needs of clients by assigning them peer

advocates and experienced paraprofessionals to help them access and maneuver through the service-delivery system. Whereas providers perhaps had no recourse 20 years ago but to rely on volunteers to provide advocacy services on behalf of their clients, today a number of organizations have trained personnel funded to help clients with specific issues or to navigate through services. Although support groups and non-clinical counseling services have been in existence for three decades or so, these services are more defined, well established and more varied today. For many PLWH/As, support groups remain a critical component of their social-support network.

In conclusion, buddy programs provide a vital resource to the community. Although the size of this report's respondent pool is small, the qualitative information speaks volumes about consumer needs. Buddy programs are essential because they attempt to fill the gaps between social support and medical care for PLWH/As. Even though buddy programs have undergone some transitions, "what hasn't changed are the essential ingredients of the buddy programs — one human being lending a hand to another in need, both of them benefiting from the exchange" (Weber 2000). Florence Nightingale would be pleased.

APPENDICES

Over the pages that follow are reproduced (a) the questionnaire that was administered to the buddy program clients and would-be clients and (b) the letter of explanation that accompanied it.

Appendix 1. Survey Questionnaire

Satisfaction Survey for the Buddy/Companion Program

1. Have you ever applied for a Buddy from the Buddy Program? Yes No
 If so when? _____

2. Do you presently have a Buddy from the Buddy Program? Yes No

3. Based on what you've been told about the Buddy program, which of the following supports do you expect from your Buddy? *(Please check all that apply and indicate the type of assistance where applicable.)*

- Companionship (someone I can talk to)
- Transportation - please indicate how often _____
- Run errands - please indicate type of errands and how often _____
- Meal preparation
- Housekeeping/homemaker services - please indicate what type _____
- Final Stage Support
- Help me talk to my care providers
- Help me talk to my family and loved ones
- Other: _____

4. Is it important that your buddy... *(Please check all that apply.)*

- | | |
|---|--|
| <input type="checkbox"/> Match your age | <input type="checkbox"/> Match your sexual preference |
| <input type="checkbox"/> Match your race | <input type="checkbox"/> Live or work in your neighborhood |
| <input type="checkbox"/> Match your religion | <input type="checkbox"/> Have personal experience with HIV |
| <input type="checkbox"/> Match your gender | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Match your interests | |

5. How many hours a week would you expect your Buddy to be there for you?

6. How long (in months) would you expect your Buddy to be there for you?

Appendix 2. Survey Explanatory Letter

Dear Participant:

The Baltimore Planning Council is a 40-member body appointed by the mayor of Baltimore City to plan health services in the Baltimore metropolitan area. It is charged with directing Title I Ryan White CARE Act dollars to most effectively meet the needs of some of the area's special population.

The Planning Council is in the process of obtaining feedback on several of its funded programs. In particular the planning council is evaluating the Buddy/Companion program. The Health Services and Resources Administration has provided the following definition:

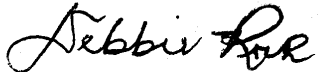
Buddy/Companion Service: An activity provided by volunteers/peers to assist the client in performing household or personal tasks and providing mental and social support to combat the negative effects of loneliness and isolation.

With this definition in mind, we are asking that you assist us by giving us your honest feedback on the questions asked in the enclosed survey.

All information gathered from these surveys will remain strictly confidential. Once you have completed the survey, please seal it in the stamped envelope provided. You may either give the envelope back to the Maryland Community Kitchen staff/volunteer or send it back to InterGroup Services.

Thank you in advance for your cooperation in this endeavor.

Sincerely,



Debbie Rock
Chairwoman
Baltimore Planning Council

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