Persons With Disabilities: Barriers and Rewards to Volunteering in Hospice Programs

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This study examined the perceptions of volunteer coordinators about persons with disabilities serving as volunteers in hospice programs. It addressed the following research questions: How prominent are persons with disabilities volunteering at hospice programs? What do volunteer coordinators perceive are the major barriers and challenges of having persons with disabilities serve as volunteers? What do volunteer coordinators perceive are the potential rewards of having persons with disabilities serve as volunteers? To what degree are volunteer coordinators willing to make adaptations in order to accommodate the needs of persons with disabilities who are serving as volunteers? How do perceptions about barriers and challenges, as well as rewards, relate to a willingness to make adaptations and to the percent of persons with disabilities volunteering in a hospice program?

Volunteer coordinators of 28 hospice programs in the Metropolitan Detroit area were surveyed in 1998 about their use of volunteers with disabilities in their volunteer programs. The 17 hospice programs participating in the study had a monthly patient census ranging from 11 to 112 with an average of 56.97.

The survey instrument asked volunteer coordinators to assess, using a 5-point Likert scale (with 1 being the least and 5 being the most) the degree to which: (1) they perceived each item on a list of 17 barriers and challenges in using persons with disabilities as volunteers; (2) they perceived each item on a list of nine potential rewards in using persons with disabilities as volunteers; (3) they would be willing to make modifications or adaptations in volunteer programs to accommodate persons with disabilities.

RESULTS

The participating hospice programs reported the number of current volunteers ranging from 6 to 300 with an average of 83.65. Of the 1410 persons reported as volunteering by the 17 hospice programs, 43 were reported as those with disabilities for a total of 3% volunteers with disabilities. Of the 17 programs, 5 programs (29%) had no persons with disabilities volunteering at the current time. One program had 12 volunteers with disabilities.

REWARDS

Table 1 reports the rank order of potential rewards of using volunteers with disabilities as perceived by volunteer coordinators. They viewed the diversity of volunteers as the greatest potential reward or benefit. The increased

TABLE 1

Perceived Potential Rewards of Using Volunteers with Disabilities

Potential Rewards	Mean Score (N=17)	Standard Deviation
Diversity	4.12	1.41
Understanding	3.94	1.24
Life Experience	3.82	1.43
Empathy	3.69	1.25
Motivation	3.58	1.42
Expand Marketing	3.47	1.46
Increase Volunteer Pool	3.19	1.60
Patient Identification	3.18	1.24
Expand Options for Performing Tasks	3.06	1.24

Notes

Mean is the average score with scores ranging from 1 to 5.

N=17; 17 is the number of hospice programs responding to question.

Standard deviation measures how widely or narrowly the numbers are spread out around the average.

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understanding, life experience and empathy that volunteers with disabilities could bring to their volunteer activities were also viewed as potential rewards.

BARRIERS AND CHALLENGES

Table 2 reports the perceptions of volunteer coordinators as to the barriers and challenges of placing volunteers with disabilities in hospice programs. Concerns for the patient safety received the highest score, followed by transportation issues, and concerns for the safety of the volunteers. They perceived the attitudes of other volunteers and staff as presenting the least barrier or challenge.

TABLE 2

Perceived Potential Barriers and Challenges in Using Volunteers with Disabilities

Barriers and Challenges	Mean Score N=17	Standard Deviation
Safety for Patient	4.35	0.86
Transportation	4.18	1.13
Safety for Volunteer	4.06	1.30
Cost in Making Adaptations	3.88	1.11
Attitudes of Caregivers/ Families	3.94	1.09
Physical Barrier of Patient Homes	3.77	1.03
Extra Supervision	3.63	1.15
Appropriate Placements	3.65	1.22
Recruitment	3.56	1.03
Attitudes of Patients	3.38	0.89
Extra Training	3.18	1.29
Retention	2.94	.97
Lack of experience/ knowledge in working with population	2.94	1.12
Physical Barriers of Hospice	2.35	1.17
Safety for Staff	2.29	1.21
Attitudes of Staff	2.24	1.15
Attitudes of Other Volunteers	1.82	0.88

Notes

Mean is the average score with scores ranging from 1 to 5.

N=17; 17 is the number of hospice programs responding to question.

Standard deviation measures how widely or narrowly the numbers are spread out around the average.

TABLE 3

Degree of Willingness to Make Adaptations for Volunteers with Disabilities

Adaptations	Mean Score (N=17)	Standard Deviation
Self-education to increase awareness of this population	4.41	0.94
Accessibility of training facility	4.00	1.23
Training time (hour, duration)	3.82	1.29
Length of training session	3.71	1.36
One-on-one training	3.24	1.25
Equipment and materials	3.18	1.19
Interpreter/signer	3.06	1.44
Transportation for volunteers	2.24	1.44

Notes

Mean is the average score with scores ranging from 1 to 5.

N=17; 17 is the number of hospice programs responding to question.

Standard deviation measures how widely or narrowly the numbers are spread out around the average.

ADAPTATIONS

Volunteer coordinators reported a willingness to make adaptations for volunteers with disabilities. The extent to which they reported their willingness to make adaptations is presented in Table 3. Volunteer coordinators reported that they were most willing to become better educated and increase their awareness about persons with disabilities. They also reported that they were willing to make training facilities more accessible. They reported they were least willing to make adaptations to accommodate volunteers with disabilities in the area of providing transportation.

PERCEPTIONS OF REWARDS: WILLINGNESS TO MAKE ADAPTATIONS AND PERCENT OF VOLUNTEERS

The volunteer coordinators' scores, about their perceptions of the barriers and challenges faced by programs in which persons with disabilities volunteer, were correlated both with their willingness to make adaptations and with the percent of persons with disability volunteering at the hospice program. Perceptions of volunteer coordinators

about the rewards of using persons with disabilities significantly correlated with their willingness to make adaptations on all measures. The overall score on perceptions about the rewards of persons with disabilities volunteering significantly correlated to their willingness to make adaptations to accommodate volunteers with disabilities ($r=.790$, $n=17$, $p < .01$). However, perceptions of volunteer coordinators about the rewards of using persons with disabilities did not significantly correlate with the percent of persons with disability volunteering at their hospice program overall or on any specific measure.

PERCEPTIONS OF BARRIERS AND CHALLENGES: WILLINGNESS TO MAKE ADAPTATIONS AND PERCENT OF VOLUNTEERS

The volunteer coordinators' scores about their perceptions of the barriers and challenges faced by their program in persons with disabilities volunteering were correlated with both their willingness to make adaptations in their program and with the percent of persons with disability volunteering at the hospice programs. Perceptions of volunteer coordinators about the barriers and challenges of using persons with disabilities did not significantly correlate with a willingness to make adaptations for volunteers with disabilities overall or on a specific measure. The overall score on perceptions about the barriers and challenges of persons with disabilities volunteering did not significantly correlate with the percent of persons with disabilities volunteering at hospice programs. However, the three specific safety barrier and challenge scores significantly correlated with the percent of persons with disabilities volunteering at hospice programs. Table 4 expressed concerns about the safety of patients, safety of the volunteer, and safety of the staff significantly related to a lower percent of persons with disabilities volunteering at their hospice programs.

IMPLICATIONS FOR PRACTICE

Findings from this study suggest that volunteers with disabilities comprised a small percentage of the volunteers serving at the hospice programs surveyed. They identified

TABLE 4

Correlation of Mean Ratings of Barriers/ Challenges and Percent of Volunteers with Disabilities at Hospice Program

Barriers/Challenges	% of Volunteers with Disabilities N=17
Overall Mean Score	-.458
Safety for Patient	-.661**
Safety for Volunteer	-.676**
Safety for Staff	-.519*

Notes to Table 4:

*$p < .05$

**$p < .01$

Correlation is the measure of the relationship between two variables. Its value can range between -1 and 1. The closer to –1 or 1 the number becomes, the stronger the relationship between the two variables is. A negative correlation means that as one variable increases, the other variable decreases.

issues related to transportation, access in patients' homes, and the cost of making adaptations as physical barriers in using volunteers with disabilities in hospice programs. They also expressed concern for safety of both the patient and the volunteer as strong barriers. Volunteer coordinators perceived the attitudes of patients as a barrier — more than the attitudes of staff and other volunteers but less than caregivers and family members. The findings suggest that although both physical and attitudinal barriers exist, attitudinal barriers may be more mixed and complex than physical barriers. The complexity of attitudinal barriers may in part stem from their often unconscious nature and may be attributed to others more than oneself (Taylor,1995).

Despite the complexity of attitudinal barriers, addressing the attitudes of staff and other volunteers is crucial if hospice programs want to successfully integrate persons with disabilities into their programs. Training and education has been found to be effective in increasing the acceptance of persons with disabilities (Mathews, White, & Mrdjenovich-Hanks, 1990) and hospice programs may want to consider instituting these programs.

Volunteer coordinators in the study viewed the strongest reward of using persons with disability as the greater diversity it would bring to their hospice programs. They also

perceived that volunteers with disability would specifically benefit patients in the increased understanding, life experience and empathy that they would bring to their work. Perceptions about these rewards are consistent with the literature suggesting that persons with disabilities may be viewed as more understanding in helping relationships because of their own life experiences (Levine, 1983; Mackelprang & Salsgiver, 1996). Volunteer coordinators may be well served to emphasize these rewards in volunteer training sessions.

Agencies should be willing to make some initial adaptations in order to offer volunteer opportunities for persons with disabilities as they will most likely reap the rewards quickly in the increased volunteer services they will be able to provide. In this study, volunteer coordinators generally expressed a willingness to make adaptations to accommodate the needs of volunteers with disabilities. They were most willing to make adaptations in the area of self-education to increase awareness but they were also willing to make adaptations in areas related to the accessibility of training facility, training time and duration of training sessions. However, they were less willing to make adaptations in areas related to transportation, additional personnel (i.e., interpreter), and the use of equipment. This finding may relate to the fact that volunteer coordinators were more willing to make adaptations in areas where they personally had input and control. Adaptations related to transportation and additional personnel often require additional resources that volunteer coordinators may have viewed as beyond their purview. However, transportation adaptations may not always necessitate additional resources, as some work can be completed in one's home, in a local community center or via the internet if physical mobility and transportation problems preclude going to an agency.

An interesting finding of the study reveals that perceptions about the rewards of using volunteers with disabilities related to willingness to make adaptations, but perceptions about the barriers and challenges of using volunteers with disabilities did not. This suggests that although volunteer coordinators are clearly cognizant of the barriers and challenges of using volunteers with disabilities in their program, this awareness is not influencing their willingness to make adaptations for volunteers. It is their perceptions of the rewards that relate to their willingness to make adaptations. Increasing the willingness to make adaptations to accommodate the needs of volunteers with disabilities may come more from increasing the understanding of the rewards. This is a hopeful finding since volunteer coordinators expressed their willingness to gain greater education.

It is also interesting to note that perceptions about the rewards of using volunteers with disabilities failed to relate to the actual percent of persons with disabilities comprising the volunteer pool. However, perceptions about the barriers and challenges of using persons with disabilities as volunteers related to the percent of persons with disabilities volunteering in a program. It was only in the area of safety that perceptions about barriers and challenges significantly related to percent of persons with disabilities volunteering in the program. Interestingly, concern for the safety of staff was relatively low, but still related to percent of volunteers with disability in a program. These findings suggest that issues related to the concern about safety appear to influence the number of volunteers with disabilities that a program will have. In today's litigious society, this safety concern may be grounded in strong liability concerns.

The small number of hospice programs included in the study limits its findings. Hospice programs vary greatly and, thus, a study including a larger number of hospice programs would offer a more accurate picture of the role persons with disabilities play in hospice programs. A future study would also benefit from learning more about what activities volunteers with disabilities perform at hospice. This data could provide richer information to assist in the development of volunteer opportunities for persons with disabilities.

Large numbers of persons with disabilities have the health, resources, skills and abilities to bring a great deal to the volunteer experi-

ence. Volunteers with disabilities, similar to other volunteers, must perform duties that are challenging, interesting and important. Many have a strong desire for meaningful and productive activities (Taylor, 1995). Volunteers with disabilities, similar to other volunteers, must also experience successes in their work, receive adequate support for their efforts, have opportunities for friendships, and receive recognition for their contributions (Fischer & Schaffer, 1993). Future research should examine the relative significance of these factors in the recruitment and retention of volunteers with disabilities in much the same manner as it has been examined in the hospice literature with volunteers in general.

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