

Editor's Note: The following article is reprinted (with updated format editions) from The Journal of Volunteer Administration, 2003, 21(1), pp. 9-24.

“It Shouldn't Be This Difficult”: The Views of Agencies and Persons with Disabilities on Supported Volunteering

Linda L. Graff & John A. Vedell
Volunteer Centre & Mohawk College
LL.GRAFF@sympatico.ca
(no current contact information available)

(Editor-generated) Abstract

The authors discuss supported volunteering and ways to help disabled volunteers to become meaningfully involved in organizations. Focus groups were conducted and qualitative input from both agencies and volunteers, disabled and non-disabled, are discussed.

(Editor-generated) Key Words:

disabilities, volunteers, supported volunteering

Introduction

“Opportunities for All,” a project focused on current and future supported volunteering in Waterloo Region, was launched by an inter-agency consortium called The Resource Group for Supported Volunteering (R.G.S.V.), formed in 1997. The Trillium Foundation of Ontario funded the project. The R.G.S.V. comprised eleven agencies whose mission it is to a) serve persons with physical disabilities, or b) promote voluntary action in the community.

Philosophy

The philosophical basis for R.G.S.V.'s activities is:

- commitment to “assisting *all persons* to participate in satisfying, productive volunteer experiences...”
Removal of “barriers to full participation by educating, and supporting community members, identifying and developing resources that promote accessibility, and supporting individuals to cultivate their potential.”

- belief “that *all persons* have the right to informed choice and equal access to fully participate in the opportunities they choose for themselves...” Belief “in encouraging independence, individual growth, mutual respect, cooperative relationships, and partnerships within an understanding and welcoming community.”

In context of the above philosophy, the overall purpose of Opportunities for All is: “To increase the community’s capacity to open up new opportunities for all persons to exercise more control over their own lives and make a contribution to this community through volunteer work.”

“Supported Volunteering” Defined

Supported volunteering is about helping marginalized persons become fully engaged in volunteering. The definition of supported volunteering typically encompasses a wide variety of marginalized populations, including, for example, persons with physical or sensory disabilities, persons

with learning disabilities, persons with emotional or psychiatric disabilities, new immigrants, and persons of diverse cultural backgrounds. In short, any indented group of persons who may need additional consideration or assistance in becoming involved in volunteering can be encompassed by the definition. It is for this latter reason that in some supported volunteering projects youth and seniors have been included in the definition.

For the purposes of the Opportunities for All project, the definition of supported volunteering was confined to “persons with disabilities.” This was because the sponsoring R.G.S.V. largely comprised organizations that provided services to that client group, and that was where the R.G.S.V. chose to concentrate its efforts in this project. The term “disabilities” was left deliberately undefined. The R.G.S.V. decided early on that any person with a disability of any nature would be eligible for consideration in this research project.

Supported volunteering can entail a range of activities. These include:

- helping prospective volunteer placement agencies increase their knowledge about involving persons with disabilities
- providing a coach for the volunteer, and/or
- a centralized placement agency that a) helps not-for-profit organizations identify, modify or develop suitable volunteer placements for persons with disabilities, b) aids volunteers who have disabilities to identify their interests and abilities, and, c) refers those volunteers to potential placements in not-for-profit organizations in the community

Supported volunteering can include interventions on three levels:

- **Individual** – support for the prospective volunteer, including placement or workplace modifications, additional training or supervision, provision of a coach for a period of time and/or provision of a partner, either initially or on a continuing basis
- **Group** – training for agencies to enable them to be more inclusive
- **Systematic** – assistance for agencies in the development of an appropriate infrastructure for management of a supported volunteering program

The R.G.S.V. hired a consulting firm, Graff and Associates, to conduct research on supported volunteering. The research design had three key components: a literature review, a survey of the current state of supported volunteering among local not-for-profit organizations in the Waterloo Region, and focus groups with volunteers, prospective volunteers and agency representatives.

This article includes emphasis on the frequently discouraging experience faced by persons with disabilities who try to become volunteers despite the apparent interest of agencies in involving volunteers with disabilities. The data indicate that if supported volunteering is to flourish, agencies must receive considerable assistance in learning how to involve and support people with disabilities. (Even some agencies that have a mandate to work with people with disabilities do not always know how to effectively support persons who have disabilities different from those whom the agency is mandated to serve.)

Focus Group Research Methodology

Based on information from the community agency survey³, and questions arising therein, it was determined that this project component needed to gather detailed information from the following populations:

- agencies that currently (or have recently) involve(d) persons with disabilities as volunteers
- agencies that have not involved persons with disabilities as volunteers
- individuals with disabilities who are currently volunteering (or have recently volunteered)
- individuals with disabilities who have never volunteered

It was decided that interaction by representatives of the first two populations and by representatives of the second two populations in the focus group setting would be instructive. Accordingly, two additional focus groups were designed:

- a combination of agencies that currently (or have recently) involve(d) persons with disabilities as volunteers *and* agencies that have not involved persons with disabilities as volunteers
- a combination of individuals with disabilities who are currently volunteering (or have recently volunteered) *and* individuals with disabilities who have never volunteered

Research Questions

A separate set of questions, created for each of the focus groups, are found in Appendix 'A.'

Sample Selection

To recruit agency representative participants to the focus groups, invitations were sent to the same mailing list that was used to conduct the community agency survey.⁴ To recruit individual participants to the focus groups, agencies were asked to pass along an invitation to any persons with disabilities that they worked with whom

they thought might be interested in assisting us with the research.

Schedule

All six focus groups were conducted in mid-September, 1998.

Reminder Notices

Reminder notices and/or phone calls were sent/made to all focus group participants to ensure their attendance.

The Sessions

The sessions were planned to run 1.5 hours, and this was the commitment made to participants.

A member of the R.G.S.V., acting as host, attended each session. The Consultant attended and introduced the focus group format and its purpose, and helped participants to understand that their contributions were welcomed at any time during the session. She indicated this was a research project and received participants' permission to tape the session.

The Consultant facilitated each session, asking the scheduled questions, and moderated conversations among participants. From time to time, the consultant or the R.G.S.V. member asked supplementary and clarifying questions.

The Sample

The sample included a total of 26 agencies, 24 (92%) were currently (or had recently) involved persons with disabilities as volunteers, and two (8%) were not currently involving persons with disabilities as volunteers. Of the latter two, one agency had never involved a person with a disability as a volunteer, and the other had what they considered only limited success in doing so in the past.

A wide range of agencies was represented among focus group participants, including representation from the following

sectors: arts/culture, disability service, fundraising, multiculturalism, seniors, recreation, local government, nutrition and food services, health, and social services.

The sample also included 16 individual representatives: 13 (81%) had recently or were currently volunteering; two (13%) had tried to locate volunteer work, but had met with only limited success; and one person (6%), not yet volunteered and had not thought seriously of doing so.

There were a variety of disability types and severities represented among the focus group participants, including the following disabilities: mobility, vision, speech, developmental, cognitive, and mental health.

The ideal focus group size was set at eight to ten participants. Respondents were scheduled into sessions as much as possible to create groups of that size.

Upon completion of the focus groups, the audiotapes were transcribed verbatim. A thematic analysis was performed on the data collected from all six focus group sessions.

The Results

The Agencies

The experience of supported volunteering from the perspective of agencies ranged from “successful” experience to “not good” experience. Some reported “mixed” experience.

The following quotation describes a success story:

We did have a volunteer who... was pathologically shy. She asked to be at that front desk and we asked her “are you sure? You don’t have to do this if you don’t want to” and she did and we helped her, we supported her...She went from being unemployable... she now works at [a

local store]. But it took two years of us saying “It’s okay...If you don’t want to do that, say... We’re not going to make you do anything you don’t want to do.”

An unsuccessful experience is reflected in these comments by an agency representative discussing interactions with volunteers with hearing loss:

...they get frustrated. We get frustrated and we lose the volunteer, which is not the ideal situation because obviously they can contribute. It’s just we don’t know how to adapt [to] their needs, they don’t know how to adapt to our needs and we get caught in the ‘we don’t want to offend you and you don’t want to offend us’ and things fall apart.

Mixed experience of both positive and negative aspects is reflected in the following commentary:

I find that it takes extra time... You have to really be concise in what you tell them. You know, give them lots of steps. But it’s worth it, because once it’s done... these volunteers do some of the jobs that the [staff] would have to do if the volunteers weren’t there. Washing the dishes, cleaning the bathrooms, doing some laundry, things like that, and that takes the [staff] away from the children. So, yeah, in the long run it’s really worth it.

Factors Leading to Success

Agency representatives identified five characteristics required for a successful supported volunteer program.

The right 'fit' between a volunteer's gifts and limitations on the one hand, and the requirements and benefits of the volunteer position on the other. A concomitant of this is the importance of being honest with a volunteer candidate if an appropriate fit cannot be found for the time being. A negative illustration of this was the statement of one agency representative, who admitted,

when we don't have a proper match between what we need and what they can give, we just don't call back, and that's not professional, I know.

The importance of providing flexibility in job design and willingness to modify positions in order to accommodate volunteers who require such support. An example of this willingness was one agency representative, who said,

...I can build a job to fit anybody, and I'm more than happy to do it.

Another emphasized the need for persistence:

In my opinion, we need to at least make the effort. Our adopted philosophy is that every volunteer is given at least three times to try it out. We together decide if its working out.

One more participant stressed the importance of flexibility when problems arise in the placement:

...we found a way to [change a volunteer's placement in a way] that she doesn't frighten people anymore. [The volunteer] thought it was a promotion.

That this is not always a simple thing to do was highlighted by a participant who spoke of the reluctance to involve persons with disabilities for the very reason that flexibility and adaptation is difficult in a frequently changing environment.

Adequate Resources

The truism that adequate resources are necessary for a successful volunteer program, especially one that includes persons with disabilities, was emphatically stated by one agency representative as follows:

That's what we're hoping this project may end up, that we can say to somebody- 'God, if you want [the volunteer Action Centre] to be finding the right niche for different volunteers, we gotta have more money here.'

Another voiced a concern familiar to administrators of volunteers,

One of the frustrations for [our organization is that] our funders have vigorously promoted volunteerism, but promote it only in terms of being a cost savings to the organization. I certainly have not seen volunteerism or experienced in the last eleven years as a cost saver... We've benefitted in many ways from the skills [volunteers] bring to the organization, but you need resources to keep good volunteers.

In support of the previous statement, another participant said,

Sometimes when we are told to support volunteerism, and when our funders tells us that, we are told to

do so only as a cost saving method, not because we have a moral obligation to do so. There's a dollar figure that must be attached to any obligation that any organization has around this table.

That same participant contemplated that policy makers, funders, and government bodies, rather than agencies, should be the target of lobbying on behalf of supported volunteerism.

Not surprisingly, participants emphasized that the lack of resources makes it difficult for agencies to enlist special needs volunteers, because special needs volunteers can require more time and resources.

An agency mission and service consistent with the involvement of supported volunteers. Some participants felt it is difficult to accept as volunteers any persons who have a disability or limitation that resembles the disabilities or limitations for the agency's client group. For example, one participant said,

Staff would say, okay, I'm giving this volunteer just as much support as what I would a member, so where do we stop, where do we say they're no longer a volunteer...?

Sometimes the nature of the client population and their specific vulnerabilities pose limits on the type or extent to which volunteers with special needs can be involved:

[A] major barrier has been [volunteers] need to have the perceptual level to understand when residents are saying things like, 'I'm going to go home,' or 'can you take me home?' that you can't take

someone out the doors, that they're confused. Judgment is important.

Fortunately, the converse can also be true, i.e., when the work of the organization lends itself to the involvement of people of all sorts, capacities, and limitations as volunteers. This was illustrated by the following offering of a participant,

...we have volunteers of every description, every disability. There isn't one that I can think of that [we don't have]... We do... a whole range of activities so we're able to be inclusive.

Clients as Volunteers

An increasing number of organizations are seeking to involve their clients ("consumers") as volunteers, in some cases on the board or in an advisory capacity. In other cases, organizations allow, even encourage, clients and ex-clients to participate in service delivery. The latter often is part of the recovery process of the client *qua* volunteer.

One organization spoke of two conditions for the involvement of their own clients as volunteers in a program: 1) approval from program clients, and failing that, 2) absence as a client from a program for six months before becoming a volunteer in the program. Another participant noted the importance of volunteering for clients, but added that it is better if they volunteer in some other agency. A third participant stressed the principle of inclusivity as it relates to special needs volunteers as well as to clients. Applying the principle, however, can lead to a "dicey" situation when the clients are reluctant to accept the ex-client as a volunteer.

Value Added vs. Volunteering as Therapy

Very few organizations exist solely to give volunteers a place to volunteer, but rather, they invite volunteers to assist with accomplishment of the organization's mission. Accordingly, the "output" of a volunteer must exceed the "input" of time, energy and resources required to achieve and sustain placement.

When input to the supported volunteer exceeds adequate return to the agency, supported volunteering moves from being "therapeutic," i.e., a useful tool in interrogation, recovery and healing, to "therapy," i.e., it becomes volunteering for its own sake. One agency representative described a situation in which this occurs. Students with special needs work along with paid staff, who later redo the students' less than adequate work. In that case, the involvement of students is chiefly of value to the student, not the organization.

In reaction to this description, another participant expressed discomfort tinged with anger:

What's the point then? To me that's tokenism. [Such a practice makes me] furious, because they're obviously not being trained and counted as a person who's doing a job.

Clearly, achieving a proper balance between the resources input required to find or create the right position for the right volunteer and the productivity output from the volunteer in the position can be difficult to achieve⁵.

The Right to Volunteer and the Obligation to be Inclusive

Even though organizations rightly can expect a "return on investment," is there a responsibility on voluntary sector organizations to expend greater effort for

special needs volunteers, regardless of an input-output imbalance? Is failure to do this discriminatory, a form of "ableism"?

A few focus group participants spoke to this question. One felt strongly that volunteers have the same rights as patrons of a facility:

As far as I'm concerned, no one gets turned away because it is a public institution, and it's my job to find a way for them to fit in... Sometimes I'm finding that it's really complex, but that's the way I feel about it.

Most who spoke, but not all, were sympathetic to this view, even to the point of saying inclusion is part of an agency's mission. The countervailing opinion was

I take pride in the fact that we are able to find and research things to match people. But that's certainly not our mission. Our mission is [providing services to our clients].

All agreed, however, with the participant who said,

I think to exclude people with special needs in the community for any organization to do that, is not creating the kind of community we are all hoping to be part of.

The Special Value of Supported Volunteering to Volunteers Themselves

The feelings of productiveness, belonging, self-esteem, and so on, that volunteers can reap from their volunteer work can have special meaning to people with special needs. Agency representatives in the focus groups supported this claim on the basis of their experiences working with special needs volunteers. They spoke of the special sense of ownership special needs

volunteers exhibit, their loyalty, and their sense of responsibility, all of which are, in effect, their contribution in return for the psychosocial rewards that being a volunteer affords.

Resistances

Administration and Board of Directors. Responses of participants with regard to the question of administrative support for inclusivity tended to be pessimistic in nature. For one participant the “biggest barrier” was the executive director and board of directors. Two agency representatives acknowledged an inherent irony: sometimes organizations that resist deploying persons with disabilities as volunteers are the very organizations that try to find volunteer (and paid work) placements in other agencies for their own clients who are persons with disabilities. An even more damning irony was underscored by two other participants, one of whom offered,

I work in an agency that specializes in serving people with disabilities, so it's rather embarrassing for me to come and say none of our volunteers have disabilities.

The second stated,
...I find it personally embarrassing... I felt... I didn't even know if I could come [to this focus group] because I use the Voluntary Action Centre to get volunteers, and I use them to place our clients [as volunteers in the community], and yet we're giving nothing back.

Clients

Sometimes agency clients are discriminatory, unaccepting, or racist. Participants noted that some clients are critical of their volunteers who are

unemployed; they do not understand that the supported volunteers' disabilities are barriers to being employed. Others spoke of the discomfort some of their clients demonstrate in the presence of multi-ethnic volunteers. There were mixed opinions whether agencies should protect their volunteers from discrimination. Some organizations believe it is not part of their mission to attempt to change the attitudes of their clients, even if those attitudes are racist. Others refuse to collude with oppression, even when it is found within their own clients or constituencies. In any event, as one participant said,

We can't always be super protective, but we need to be open and honest and communicate that to [volunteers] in all fairness to them.

Staff Members

Clients are not the only source of resistance or discrimination that special needs volunteers might expect to encounter in some settings. According to the agency representatives, agency personnel can sometimes be discriminatory, but resistance mostly falls into other categories. There may be union concerns about losing positions. Staff members may perceive volunteers, especially volunteers with special needs, to be a burden that requires extra work training and supervising volunteers. Also, some volunteers seek to socialize with staff members, many of whom do not have the time. “Volunteers drive me nuts; I can't get my job done,” is a common expression by one agency representative's employees.

It would be incorrect, however, to think that all personnel, or personnel in all organizations, are resistant to the involvement of volunteers or to volunteers who have disabilities. For example, one agency representative reported

[They] come to our team meetings, meet with our [staff]. We consider them part of the agency...like they're the professional coming in and providing a service to us, like a consultant would.

What Would be Helpful?

Participants offered much information about what they would find helpful in their development and operation of supported volunteering programs. Their thoughts are clustered into a number of specific areas.

Information on How to Work with People with Disabilities

One participant stressed the importance of open communication about limitations and accommodation needs. Persons in organizations that do not directly serve people with disabilities can find the thought of working with them scary, intimidating, or uncomfortable. The greatest fear is of being offensive to prospective volunteers. For example, one representative would be interested to know if a volunteer would be offended if asked about his/her ability to read and write.

Others stressed the need for basic information about various disabilities and how to work with people with disabilities said provision of information could become the purpose of a cooperative community project.

Staff education was also cited as important. Internal and external "educators" could be important resources.

The most striking comment about the need for information came from persons that serve persons with disabilities, viz., that they feel discomfort in working with people with disabilities different from those found among their own client group. One participant, who works for an organization serving clients with a specific disability,

noted how that organization works cooperatively with two other organizations, each of which serves clients with a different, specific disability. The goal is for each of the three to become knowledgeable about the types of disabilities clients of the other two organizations have. This approach could work equally well for those seeking information about work with volunteers having disabilities.

Ongoing Support

Initial information is critical, but an ongoing source of information and support is also of great help to agencies integrating persons with disabilities as volunteers. A support worker, who places people with disabilities, finds that her availability contributes to the confidence and success of the volunteers to whom she is available.

Support is important also for those who supervise volunteers with disabilities. A participant spoke of receiving help from another agency to solve the meaning of a verbalization of a volunteer whose communication impairment made it difficult for her to make herself understood.

One agency representative said it well,

We'd need a lot of support; someone to come in and say these are the issues, and this is how you deal with the issues.

Help to Convince the Board

One representative felt that assistance from outside is needed to help convince administrators and board members of the value of involving special needs volunteers:

...having some sort of background materials [so] we could go to the Boards and say, this won't take all my time or, this will not end up being an embarrassment to you, this will

*be a good thing for you, you will
look good, let me do this.*

Volunteers' Honesty and Disclosure

Several agency participants noted the importance of prospective volunteers being forthcoming about their own needs and limitations, for example,

The key for us has been the more honest the volunteer is with us in the beginning, the less we're putting out fires down the road.

And,

...the [placements] that were positive resulted from up front and open communication from the beginning.

Assistance with Job Design and Accommodations

Noted occasionally was the need for help to be creative with job design and accommodation possibilities, especially for prospective volunteers who have multiple disabilities.

The Role of Referral Agents

According to one participant, in referring a person with a disability to an agency for volunteer work, the referring worker needs to

know the services of the organization that you're going to be referring someone to, and know what their restrictions are in terms of resources [and] opportunities...

Another participant warns against giving the agency to which a person with special needs is referred too much information about the prospective volunteer lest

biases and preconceived notions...get in the way of getting to know the person.

The Role of Volunteer Centres

As one agency representative put it,

...the connection with the Voluntary Action Centre is so crucial, because I get most of the referrals from there. The recruitment coordinator needs to know what our barriers and limits are, who we can accept and work with.

Special Difficulties

Mental Health Issues

Several participants said they find mental health issues to be the most difficult or scary to deal with among volunteers with special needs. Unpredictability, excessive need for support, and brevity of commitment are some of the difficulties participants identified as associated with involvement of volunteers with mental health problems.

Multiple Disabilities

Some participants spoke of the increased difficulties involved in placing special needs volunteers if they have multiple disabilities. One spoke of a volunteer who can't use his hands and whose speech is difficult. The problem for the agency in such a case is the demand on time that such a volunteer makes.

Another participant agreed that persons with multiple disabilities require lots of time, but that they have much to contribute:

It's just finding the right niche...Just trying to help them, that's what you want.

Prospective Volunteer Fears

Among a variety of other difficulties mentioned, is, as one participant put it, a prospective volunteer's

...lack of confidence, depression, fear, anxiety, and they can't afford the bus fare...

Some such persons need support workers to accompany them at least in the initial phases of the volunteer placement. This in itself can become a deterrent to volunteering, especially when the position involves one-to-one visiting or companionship.

Accommodations

While it is important to remember that not all people with disabilities will need accommodations in their volunteer placements, it became clear in the focus groups that a great variety of accommodations is required in support of volunteer involvement.

Some volunteers need assistance with writing. Other volunteers need attendant care. One volunteer, a board member with vision impairment, was helped by using taped board minutes.

Many agency representatives made note of the extra time they spend with special needs volunteers, putting together the appropriate set of tasks into customize jobs that correspond to volunteers' abilities. A participant who works with a volunteer who has excellent phone manner and can write down messages gave an example of that. The job being considered for the volunteer also happened to include some tasks that were beyond her ability. The job was redesigned to accommodate the volunteer's capacity.

Deliberate vs. Accidental Inclusivity

One theme that arose consistently throughout the sessions with agency representatives is that supported volunteering rarely results from deliberate recruitment efforts on the part of the agency. Organizations are not systematically seeking special needs volunteers. Not one agency representative in this research indicated they the agency had launched any special recruitment drives or included any affirmative action messages in their regular marketing and recruitment activities.

Managers of volunteers will consider accepting people with special needs if the latter make the effort to apply, or if a third party referral agency makes the approach on behalf of the volunteer. The only exception is at the board level. Ironically, some boards deliberately seek consumer representation on the board, and in some cases, these consumers are people with disabilities. Some of these boards are the same boards that resist the involvement of people with disabilities through supported volunteering at the direct service level!

The Volunteers

Three focus group sessions were held with people with disabilities who were volunteers at the time the sessions were held. Their responses to questions were categorized, and are listed below.

Motivation

Participants related a wide range of motives for their pursuit of volunteer work. Here are some sample comments.

I think that my volunteer experiences had to do with finding out about something that really mattered to me, or knowing something was already there that really mattered to me. I wanted to support a cause that I was interested in.

I had been having some difficulty getting some full time paid employment, and I am qualified to work in that area. I thought that volunteering might help me in getting some contacts, and in showing people I can still do the job in spite of the fact that I have some visual impairments. So for me, it was...showing people that I do have the skills, and I do have the abilities, and that they were able to trust me, and I was able to develop trust as well. It [also] helped me to further develop career goals. I then went back to school and...decided to look at more of a social work profession, and doing the volunteer work allowed me to see if I had the people skills.

I've seen a lot of organizations, when they're fundraising, use the slogan, "Because you'll never know when you'll need it." To me, I think that's absolutely terrible. I think you should just be able to help people.

The Rewards of Volunteering

Participants stated clearly and enthusiastically what they get back from their volunteer work.

If they were to call me next year, I would go back again, because I felt good, happy that I helped kids. They looked up to me, and that felt really good.

They found me a real neat place to volunteer. They care a lot about people, and they care a lot about me. It's wonderful. Some days I don't feel that good, and it still feels good that we can share our feelings for

each other...we can find the support that we need.

I like the fact that I can help people. When they ask a question, I can find the information. It makes me feel good about myself, because I can help them.

It's rewarding. I'm thinking of my teaching types of volunteer things, and I find it very rewarding when you see that light bulb go off in somebody's head that tells you they understand what it is you're trying to teach them.

Volunteering is fun. You meet different people that you wouldn't normally meet. People don't generally know how to talk to a person in a wheelchair, or go out of their way to talk to a person in a wheelchair.

People like me. They say, "Good morning! Welcome back!" I always am happy.

Deliberate vs. Suggested Involvement

Almost all volunteers in the focus groups were referred to volunteering through an agency from which they were receiving services. This was not surprising, because contact had been made with prospective focus group participants through disability-serving agencies; they would naturally refer their clients and ex-clients. Because of the skewed sample in the focus groups, therefore, it is not possible to comment on mechanisms used by other persons with disabilities to find their way into volunteering if they are not receiving services from an organization that encourages voluntary action among its clients.

Six of the sixteen participants identified that they had also used the placement assistance services of the Volunteer Action Centre, often in cooperation with the original referral agency.

Barriers to Involvement in Volunteering

Focus group participants experienced a number of barriers in their pursuit of volunteer work.

Physical Limitations, Accessibility, and Accommodation Requirements

Here are two quotations that illustrate some of the frustrations that volunteers with disabilities can encounter.

The bathroom was a bit of a problem, because the door that I could get through was a fire door, and we had to find a way to leave that door open so I could get in, but it was a fire door.

I have a motorized wheelchair...this is good and bad. When I travel, I need a vehicle that can accommodate this big chair. I always find that...[it] is a real problem when it comes to reaching things. This means that file drawers and high cupboards are out of my reach. Even a photocopy machine is difficult. At work I'm responsible for ordering supplies and putting them away, and the supply cupboard is not accessible.

Transportation

The greatest number of participants noted transportation the most often as a barrier to volunteer involvement. Although public transportation was available for people with disabilities in the study community, pick up was often inconvenient. Some focus group participants had to leave

their volunteer positions early because the transportation service arrived early. Others were observed waiting for transportation up to 20 minutes after a focus group session.

Expertise of the Placement Agency

Several of the participants who had experienced the most success in their volunteer work had placements in disability-serving agencies, and in particular, in agencies that serve clients with the same issues or disabilities as the volunteers themselves. In these cases, physical accessibility, attitudes, supportiveness and job design solutions all contributed to successful placements. Unfortunately, however, this openness cannot be taken for granted, as was suggested by one respondent:

It's ironic that most agencies that want to involve volunteers in volunteer work are helping the handicapped and yet they won't have them in their own organizations.

Negative Attitudes and Ill Treatment

Some of the focus group participants encountered appalling attitudes and hurtful reception in their efforts to find volunteer work. The responses in this regard were so strong that they have been summarized below in a separate, major section of this article.

Family Overprotection

Several participants need to struggle to overcome the overprotection of their families in the process of getting out, getting about, and finding volunteer work.

...my mother said I wouldn't make it, and I did make it, and I proved to her that I could do it. My mother said, "You can't do it," and I said, "Oh yes I can!" I said, "I want to try and I want to express to you that I can do

more things as a volunteer and be more independent and go to meetings and do things on my own and decide.”

In response to the above, another participant said,

I'm relating to the mother issue. I think that growing up, I was always given the message, even though it was never said in a mean kind of way, "You can't do that." and "Oh, we can't ask you to do that," so I grew up thinking I couldn't do anything. It was big time protection.

A third volunteer added,

My sisters too. Sometimes they protect me. Sometimes you don't need that protection. You need to grow up on your own and say how you feel.

Accommodations Required

Depending on the nature and severity of the disability, accommodations required by volunteers ranges from significant to virtually non-existent. There was, therefore, a variety of needs expressed by focus group participants, most of which are summarized here.

Physical accessibility was an issue for those in wheel chairs. Patience with, and assistance for, those with severe speech impairments is important. The visually impaired and legally blind volunteers require help ranging from bigger labels for key items, to advanced software and taped minutes of meetings. A participant who uses a walker requires help getting through heavy front doors that do not open automatically.

Participation in Problem Solving

Participants were asked what they found helpful with respect to the location or creation of satisfying volunteer placements. They spoke a lot about creative problem solving, and their role in finding or making accommodations that will work.

So I said to the...supervisor, can we make the nametags big and bold in big letters and that worked out just fine.

I was on the board [of directors] in a location that was very dimly lit, and that was difficult for me, because I need good lighting...they started to give me a copy of the board minutes in a larger font....when I started [receiving board minutes in advance], ...I could use my own equipment at home, and that allowed me to read it in advance.

Being able to articulate one's needs was noted as an important asset.

When I go somewhere...I will tell them what my needs are...I don't think it's fair of me to go to a meeting and ask you to [meet my needs]. You don't know what my needs are...I always figure it's my job to put you at ease. That gets us through the first couple of meetings, and afterwards, people start saying, "Would it be easier if we do this or that?"...But it's important for me to start the ball rolling by making people feel comfortable.

Two participants discussed the importance of fighting for what is needed, and never allowing a situation to go unchallenged, because it will only make it

harder for the next person to break down that barrier.

When you come up against a problem, you have to solve it, because that gives that agency, and whoever they talk to, the ability to use that experience... Sometimes it doesn't matter what you are talking about; if people have preconceived notions, they're going to keep them, but you need to address them and say "can we resolve this?" If not, then you move on. You don't just leave... Unfortunately, if there's a disability or a minority, or whatever, the next person coming behind you will have a harder time because you've already made it an okay practice if you don't object.

Several participants agreed that if the will to solve problems is not present in the placement organization, the struggle to find solutions is much harder.

Education for Staff

Several participants believed that persons who work with volunteers could benefit from education about disabilities and accommodations.

I think that non-disabled people need to become more educated about a variety of severe and non-severe disabilities, and when people really understand a little bit more about what it's like to have a certain type of disability, and what it takes for that person to really function in the community, then I think they will truly have some understanding.

I've been in an employment situation with an agency that specifically worked with disabled persons and they, themselves, were not able to

accommodate my visual needs, and my employment was terminated. I was just let go. I really firmly believe that it takes a lot of education and a real understanding before you get a workable thing happening.

Negative Attitudes and Ill-treatment

Perhaps the most dramatic, and discouraging, revelations that came from these focus groups were the appalling attitudes and hurtful reception that participants had encountered in their efforts to find volunteer work. In the first example, the volunteer needed accessibility for her wheelchair. In her first tries to volunteer she was confronted by physical barriers, and the treatment she received from various agencies along the way was shameful.

I called [a local agency] and they had me in for an interview, but then they didn't call me back. I called them back and said, "Where are we here?" And they said, "You'll get called back," and so I waited for a week and I called them back. They said, "We don't want you here because we don't need you here," so, scratch that idea. Apparently, what they didn't tell me was that there were stairs to get into the place- and me, I can't get up stairs. When I called them back, I asked them is your place accessible, and they said yes. But when I went there for the interview, I found that they had stairs. I said, "I thought your place was accessible?" And they said, "well, we're sorry, we forgot to tell you that we've got stairs." I said, "You fibbed!" I said, "I was believing that you were actually going to need me." They said, "Well, call us back and we'll reconsider,"

but the reaction I got was they didn't need me. So scratch that idea.

Other volunteers, who often need only minor accommodations, and a bit of creativity, have had to push hard for their rights or struggle to find solutions.

I didn't have trouble with accessibility, but in terms of vision issues, yes. If I had gone to a particular place to volunteer and say I have vision issues, usually I get "Oh, hold the phone here!"

So I asked the person [where I volunteer]- she wanted me to roll money. I said, the rolls are too small and the print is too small. So she says, we'll make a chart up for you with the coloured squares, and we'll put the amounts beside the squares and all you have to do is look at the charts. I said, gee, we could have done this before. I am so frustrated. I would like to help you with your workload, but if you can't help determine what I need to help me, I can't do the work.

Here's what one volunteer observed about attitudes among volunteer agencies towards people with disabilities.

The one thing I wanted to mention, I really believe- and I don't want to be discriminatory here, because I'm not that way at all- but I truly believe that people who do not have disabilities have a harder time dealing with people whose disabilities are more severe or not. I have a visual impairment, and I am legally blind, but I don't tend to look blind. I don't walk with a cane, and I don't have a dog. I have friends who

are totally blind who do walk with a cane and have a dog and they have a lot more difficulty than I do.

Several volunteers described experiences that insulted their dignity.

...they placed me...working at the database. After two weeks they put me in a separate room and every time I needed a new piece of paper I had to go out of the room and a long way away to get it. I said, this is not safe for me or them...and I'm not doing it....There must have been a negative attitude there...I have to fight every day for what I need.

I went through five weeks of training and at the end of it they said, most of our kids need physical activity and you can't do it, so we can't match you up with them. I was quite upset...I don't understand it, and I've never understood it. I can understand what they said that a lot of their kids have aggression that they need to let out, and so we can't match you up with anybody because all of our kids need to do sports and all of that, and I'm sure that's true, but to make a blanket statement that they can't match you up with somebody...it probably would have felt awful no matter how it happened, but I think it was pretty stinky of them to let me go through the whole training program and then tell me. Why wouldn't they have said right off the bat, we need somebody who can be physically active with these kids? They made me go through all of that and then told me, "No."

In this example, the difficulty is in the circumstance and the setting.

I'm not sure it's a negative attitude, but at a lot of functions, I need to go to where everyone is standing around and it is noisy and they can't hear me talk. I have a soft voice, and for them to bend down, it's uncomfortable for them, so I avoid a lot of those functions because you end up sitting by yourself a lot of the time. It's a combination. First, wheelchairs make people uncomfortable. Having a dog has been a big benefit because he breaks down barriers, but then when people are having to bend over to speak with you, they are uncomfortable and they feel like they are invading your space. Plus it's hard to hear. In most functions, if they could have a place where people could sit, it would make a difference.

A volunteer who has severe multiple disabilities has tried hard through a number of positions that have not worked out for him. He is not completely discouraged yet, but the experience has been difficult. His conclusion is this:

They do treat you differently from other people. It's not right and it's not fair.

The Future

When asked whether they would pursue more or other volunteer work in the future, focus group participants displayed a consistent undercurrent of fear and reluctance as they offered guarded responses. This non-verbal undertone may be a better indicator than words of the struggles people with disabilities go through to find volunteer work.

Advice for Others

Despite their fears and the difficulties, participants had generally rousing, enthusiastic advice for other people with disabilities seeking volunteer work. This response came from some of the same participants who expressed some fear for themselves and their future search for volunteer work.

I would say go for it! Volunteer where you want to volunteer.

Stick at it.

Make sure you like it.

Know what you want to do. Have an idea in your head and don't be afraid to try it. You have to have some courage.

It's important to get out there and try to network...So, word of mouth-people working together to connect you...Use your contacts.

One participant gave sage advice about realistic expectations:

I'm really practical, so I'd say, if you're going to volunteer, be realistic about it. Don't volunteer to be an astronaut if you don't even know how to do less. Your skills need to match the thing you want to do.

Others recommended getting some help:

Go to the Volunteer Action Centre.

Go call the K-W Habilitation Centre to get some help to get involved.

Help in the Future

Participants were asked to comment on what they thought would make their future search for volunteer work easier.

Having contact people in agencies.

Agencies have to understand about different disabilities and where people are. Not to be afraid.

...education around volunteer opportunities, or whatever, but I think some education for ourselves around assertiveness and how to say, these are my needs or how to feel comfortable.

Some more ideas about who to call, where, what, when, how.

Summary and Conclusions

Because the purpose of the OPPORTUNITIES FOR ALL project is “to increase the community’s capacity to open up new opportunities for all persons to exercise more control over their own lives and make a contribution to this community through volunteer work,” an initial assessment of where the community is with respect to supported volunteering was an essential starting point for this project. The goal of the focus group research was to obtain more detail about supported volunteering in the Waterloo Region than was gathered in the initial community agency survey⁶.

The focus group research, based on six separate sessions with a total of twenty-six agency representatives and sixteen individuals, should not be considered a comprehensive overview of supported volunteering as it has been experienced by all, or even by a majority, of agencies or volunteers or prospective volunteers in the Waterloo Region. Information gathered here

has allowed identification of key observations and issues about supported volunteering as experienced by this subset of agency and individual representatives. The data gathered here may be useful to guide further research.

Many organizations in the Waterloo Region are deploying volunteers who have disabilities, and there was a general sentiment among agency representatives in these focus groups that this is a good thing. Most agencies would fall short of feeling that they have an obligation to do so, but most felt that inclusivity is consistent with organizational values and a reflection of the type of community we all want to live in.

Other observations from the focus group research include:

- Involving people with disabilities as volunteers is not always easy and not always successful. It can absorb more time and energy from organizations and staff, all of whom are pressed to work harder in light of cutbacks and increasing service demands. Although it cannot be said with certainty how pervasive this pattern is, some staff in some settings are resistant to the involvement of volunteers in general, and seemingly even more resistant to involvement of persons with disabilities as volunteers. This resistance is, at least in part, due to increasing work pressures on staff through the service system, although discrimination and prejudice seem to play a part as well.
- Many agencies indicated a need for information about disabilities and the process of job accommodations, as well as a further need to learn how to work with people with various kinds of disabilities. Discomfort, ignorance, and embarrassment stand in the way of creative job

accommodations and problem solving. Agencies also indicated a strong need for consistent sources of information and support- someone to call when help is needed- during the course of placements.

- Referral agents need to learn more about the nature of work and the limitations of prospective placement agencies, so that the volunteers who are referred have a good initial chance of finding success.
- Even though a significant proportion of placements do not work out or are short term, other placements, even those of a short term nature, turn out to be extremely productive, and play important roles in the happiness, well-being, and recovery of the volunteers engaged in them.
- It seems that for many volunteers who have disabilities, relatively minor and low-cost accommodations have made enormous differences in how possible and comfortable volunteer work can be. Without question, however, some participants need substantive accommodations, which when already present- as in the case of elevators and ramps- are nearly taken for granted, yet which pose absolute barriers when not in place.
- Some participants need help to determine what kind of accommodation would make the difference, but most of the volunteers in this research seemed able to identify immediately what their own needs are through long experience navigating through the other aspects of their lives.

The general conclusion drawn from this research is that, overall, locating suitable and satisfying volunteer work has not been easy for the largest proportion of volunteer

and prospective volunteer participants in these focus groups. Most have encountered barriers and negative attitudes. Many have had to try several placements before finding one that works. Although this can be said of anyone seeking to do volunteer work, some of the respondents in this research have experienced hurtful encounters and rude and inconsiderate behaviour along the way. Many feel trepidation when thinking about having to find new or different volunteer work in the future. Nonetheless, they are, as a group, enthusiastic about their involvement.

Volunteer work responds to a wide range of motivations, and is mostly a positive, rewarding, and enjoyable experience once the specifics of the position are worked out. Most of the participants in these focus groups found their volunteer work with the assistance of disability service agencies and the Volunteer Action Centre. Given the struggles they have encountered along the way, one wonders how other people with disabilities would manage without the assistance, information, and advocacy of referral agents such as have been involved with those in our research groups.

Although barriers to persons with special needs to do volunteer work are significant, they are surmountable. Success has often been due solely to the persistence and perseverance of the prospective volunteers who have continued to search for placements even after encountering obstacles, rudeness, and insults to their dignity.

For more information about the study or R.G.S.V., contact:
Opportunities For All Project
c/o Volunteer Action Centre of
Kitchener-Waterloo
68 Queen Street North
Kitchener, Ontario, Canada N2H
2H2, Tel.: 519-742-3610

Endnotes

¹ Formally known as The Regional municipality of Waterloo, Waterloo Region, located 100 kilometres west of Toronto, comprises the cities of Waterloo, Kitchener and Cambridge, plus several towns and rural areas. The population of the Region in 1998 was 418,000, representing 155,590 households.

² Association for Volunteer Administration (Winter 2000). *Opportunities for All-The potential for supported*

volunteering in community agencies.
Richmond, VA.

³ Ibid., pp 10-16.

⁴ Ibid.

⁵ Nevertheless, it is important to note that the agency survey found that the input of resources to support volunteers with physical disabilities was often minimal.

⁶ Graff and Vedell, op. cit.

About the Authors

At the time of the article's original publication:

Linda L. Graff was the Director of the Volunteer Centre in Hamilton, Ontario, Canada for nearly 10 years and has spent the last 13 years operating her training and consulting firm LINDA GRAFF AND ASSOCIATES INC. Linda is the author of eight books in the field of volunteerism, including *By Definition* (policy development for volunteer programs), *Well-Centred* (policy development for volunteer centres), *Beyond Police Checks* (screening volunteers and employees) and *Better Safe...* (risk management for volunteer and community service programs). She specializes in training and consulting on topics such as risk management, screening, policy development, board roles and responsibilities, trends and issues, and discipline and dismissal.

John Vedell retired in December 1995 after twenty-one years as executive director of Family Services of Hamilton (Ontario, Canada). Before entering the social service field in 1969, John served as a chaplain to Lutheran students in various universities in eastern Canada. He currently teaches life span psychology at Mohawk College in Hamilton, Ontario; is Secretary of the St. Joseph Immigrant Women's Centre of Hamilton board of directors; and is a volunteer peer reviewer in Family Service Canada's accreditation program.