

# Impact

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Feature Issue on Volunteerism by Persons  
with Developmental Disabilities

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Vernon Tischler (front) is a young man with Down syndrome who is making his St. Paul, Minnesota, neighborhood a good place to live for all by volunteering his time and talents in a variety of ways. His contributions were recently acknowledged in an award ceremony. See story below.

## ***"I Know I Have a Lot to Give Back": Volunteer of the Year, Vernon Tischler***

by Vernon Tischler and Kris Schoeller

*This past May, Vernon Tischler received the David L. Sons Humanitarian Award for his dedication to volunteering in the West 7th Community of St. Paul, Minnesota. This award is given each year to a person in the community who has given selflessly to others. Vernon is a friend, coworker, volunteer, and son who cares about the person next door, the kids in school and church, his friends, and anyone else he meets along the way. He came into my life a few years ago because he has Down syndrome and received an authorization from the county for support in the community, which I provide. But, mostly Vernon has been my friend. He always lifts my spirits and softens life's hard knocks. He is a writer, artist, dancer, and a singer. He reads my thoughts and my heart, and for that I am grateful. I wish that everyone could spend time with him and get to know him as I do. He is a very wonderful man.*

*I asked Vernon to share his thoughts about his volunteer activities, and why volunteering is important to him and to the community. His words are below. – Kris Schoeller*

On May 15th, 2001, I received the David L. Sons Humanitarian Award for volunteering and helping people in our neighborhood. I was very proud and so were all my family and friends who came to the dinner. I wore a suit and gave a speech and I wasn't nervous because my family and friends were all there to cheer me.

*[Tischler, continued on page 26]*

## ***From the Editors***


*The United Nations General Assembly has proclaimed 2001 to be the International Year of Volunteers. Through activities sponsored by organizations around the globe, the value of volunteerism is being noted, and the contributions of volunteers are being honored. Among the goals of the year-long celebration are increased awareness of the many ways in which people can and do volunteer, and increased involvement of individuals and organizations in volunteering.*

*One group of people historically thought of exclusively as recipients of volunteer service, rather than providers of it, are people with developmental disabilities. Too often defined by their "dis"-abilities rather than their abilities, they have been overlooked in many efforts to involve individuals in the improvement of their communities through giving of time, talents, and energy on a voluntary basis. The result is that our communities have missed out on their contributions, and individuals have missed out on the rewards of rendering service.*

*In this issue of Impact are articles that seek to encourage steps toward the greater inclusion of persons with developmental disabilities in volunteerism. The strategies and visions presented provide a wealth of ideas for supporting that inclusion, in this celebration year and in future years.*

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# Volunteer and Service Opportunities for People with Developmental Disabilities

by Bonnie Shoultz and K. Charlie Lakin

Voluntary service, community service, and service learning offer many possibilities for persons with developmental disabilities to contribute to their communities in ways that bring them the joy, sense of belonging, opportunity to learn, and respect that come to all who contribute to the well-being of others. Such service additionally provides a means to overcome historical and current barriers to full participation in society. In considering these three service options, familiarity with the distinctive

***Voluntary service, community service, and service learning offer possibilities for persons with developmental disabilities to contribute to their communities and to the well-being of others.***

features of each can be helpful in designing and selecting opportunities that offer a good match between the individuals who desire to serve and the available service activities and needs.

Voluntary service, community service, and service learning may be described in the following ways:

- *Voluntary service* has at its foundation the essential meanings of *voluntary*: It arises out of one's own free will, it implies freedom of choice and lack of external coercion, and it reflects an individual's decision to give willingly of time and ability to an activity that fulfills purposes and achieves goals valued by the individual. Voluntary service is performed without financial compensation.

- *Community service* has at its root generally acknowledged needs of the community and actions by community members that respond to those needs. Community service is defined from the perspective of the community rather than the servant. Community service can be provided with or without compensation (e.g., AmeriCorps or Peace Corps participants received limited compensation). It can be performed with or without coercion or free choice (e.g., "community service" as an imposed penalty for legal infraction or as a requirement for high school graduation).
- *Service learning* uses community service as a vehicle to enhance individual development. It engages individuals in activities that are valuable or even necessary for the community, but does so for the purpose of achieving learning objectives. Those objectives might include improving social or employment skills, building self-confidence, encouraging social responsibility, promoting empathy, fostering environmental awareness, and so forth.

The whole issue of voluntary service and tangible rewards for valuable, real work for people with developmental disabilities carries some historical baggage that must be addressed. Many people with developmental disabilities were, until recently, forced to work for no pay in both institutions and community settings. We have personally known people who were "paroled" from institutions into nursing homes where they were expected to work 60 hours a week for room, board, and a \$5 a week stipend. They "volunteered" their time because of the coercion of knowing that if they did not, they would be returned to the state institution. In the 1960s and 1970s, courts intervened to pronounce

such "peonage" illegal. But in the 1980s, the supported employment movement created new debates over "voluntary" work (also called "extended training") and whether it constituted exploitation to ask people with developmental disabilities to do on an unpaid basis that for which others were paid, even though they were provided integrated work opportunities with the possibility of eventual paid employment as they developed skills and became acquainted with other workers (Bellamy, et al., 1984; Brown, et al., 1984). As a result of such controversy, many agencies have focused only on paid employment. But, increasingly, as volunteerism and community service have been promoted on the national, state, and local levels, more people committed to the well-being of persons with developmental disabilities (self-advocates, parents, providers, and professionals) have recognized the real value that performing service can bring to the lives of all citizens.

Volunteerism and community service have been avenues through which individuals have been able to improve their communities, gain marketable skills that could eventually lead to paid employment, test out interests and possible career paths, develop personally and professionally meaningful social connections, and experience the pleasure and satisfaction of the activity itself and of making a difference in the lives of others. For the many individuals with developmental disabilities who are dissatisfied with the limited options they have traditionally been offered to obtain these benefits, voluntary and community service, and service learning, may be an important alternative, and may have the added consequence of contributing to changing societal attitudes and opening doors for persons with disabilities that are now too often closed.

There are a number of specific barriers that have often made it difficult for individuals with developmental disabilities to participate in these service options, and these barriers must be addressed on the societal, organizational, and individual levels. Barriers include:

- Persons with disabilities may not be aware that voluntary service options are available to them, or they may not have the support they need to get to pursue the options and participate successfully.
- The gatekeepers (volunteer coordinators, nominating committees, etc.) in the various organizations to which individuals with developmental disabilities may apply may need education and support in thinking about how people with developmental disabilities could contribute, or could be supported in the volunteer work they might be doing.
- Agencies supporting adults with disabilities, and school teams and staff supporting students with disabilities, have often not included discussion of voluntary community service opportunities in their support and personal planning services.
- The programs and facilities of organizations involved with voluntary service, community service, or service learning may present barriers to persons with disabilities of which the organizations are unaware. These may be interpreted by persons with disabilities as evidence of a lack of interest or welcome.

In overcoming barriers and creating opportunities for service to others by individuals with developmental disabilities, it can be helpful to ask the following questions as a starting point in attending to the fit between the person and a particular option, and also in evaluating the ability of volunteer, community service, and service learning organizations to include individuals with disabilities:

- Does the individual have interests or passions that can guide efforts to

identify and support service involvements?

- Are there existing opportunities that would allow the individual to pursue those interests and passions in a manner that provides service that is of value to the community? If not, can such opportunities be created?
- Are there specific learning goals of the individual to which certain service activities might contribute?
- Are necessary supports available to enable the person to participate in the service activity? If not, how can they be created?
- Is the service activity supported by adequate and appropriate intrinsic reinforcers (e.g., integration, acceptance, respect, recognition, tangible rewards)?

The world is changing for people with developmental disabilities. Doors are opening that were once closed, and the doors to community involvement in the form of voluntary service, community service, and service learning are among those that must be opened wide.

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## Giving and Receiving: Kira's Story

*This past year, Kira Fisher was an AmeriCorps participant with Action for Children Today AmeriCorps in Chapel Hill, North Carolina. She provided programmatic support and time release for teachers in a childcare center. Of this experience she has the following to say:*

*My service included teaching literacy, team-building exercises, and pre-kindergarten skills. I served in an inclusive classroom in which one-third of the children had disabilities. I made a big difference with the children. One of the student's mothers came to me and said that I was a wonderful role model for her daughter who had cerebral palsy.... I was able to help [two children with cerebral palsy] with daily living skills, and this helped me grow as a person. I was able to teach them and show them what they needed to learn and what they could achieve.... [Through this experience] I gained insight into what I want to pursue in graduate school. I will use my educational award to pursue a masters in Early Intervention Education, working to include children in all kinds of classrooms regardless of where they come from or what level they are at.*

Excerpted with permission from *Service & Inclusion: A Multimedia Resource for Inclusive Community Service*, a Web site developed by Emily E. Miller through her fellowship with the Corporation for National Service ([www.serviceandinclusion.org](http://www.serviceandinclusion.org)). The Web site includes transcripts of interviews she conducted with 32 national service participants who have disabilities.



## Why Bother? How Persons with Disabilities Benefit as Volunteers

by Angela Novak Amado

Volunteerism by persons with developmental disabilities can be individually meaningful as well as valuable for the larger community. While volunteerism has historically been too often distorted into a substitute for “real life” and another form of devaluing, congregating, and exploiting persons with developmental disabilities, with insightful planning it can provide huge benefits for people with developmental disabilities. Five areas of benefit are discussed here.

### ***Social Inclusion, Community Membership and Friendship***

Given the social isolation of many people with developmental disabilities, volunteering is important and one of the most useful avenues for really getting to know other community members. The social lives of many people with developmental disabilities often consist of “activities” and “outings” such as shopping or attending movies, without genuine opportunities to get to know others. While people with disabilities are physically located in community homes, they are often socially not really full community members; they often go visit “the community” (everything outside the front door) like tourists. While sometimes community members may recognize and greet them, the degree of real friendship is often limited.

Typically, the only way any of us become friends with anyone else is that we get to know each other over time – seeing the same people in the same place, over time, with some activity shared in common. Volunteering alongside a wide variety of community members is one of the best means there is to naturally promote people getting to know each other, appreciating and befriending each other, and experiencing true belonging.

Ask any group of people where they got to know the friends that they have,

and one of the frequent responses is that people became friends with others with whom they shared volunteer activities. For example, people get to know each other in their faith communities not primarily by attending services at the same time, but by being part of the committees and activities that contribute to that community’s life. Another example is one of the most innovative programs in the country, the City of Seattle’s Involving All Neighbors program, which is run through the City of Seattle’s Department of Neighborhoods. People with developmental disabilities get involved in all kinds of neighborhood activities and programs with their neighbors, from painting murals to community gardens to cleaning up the river. Through these shared activities, many friendships between people with and without disabilities have blossomed.

Another frequent response to the question of where people met their current friends is “through work.” While efforts to promote volunteerism should never displace finding jobs and increasing the income of people with disabilities, many people with limitations in their abilities and vocational opportunities will not have the chance to befriend others through work; volunteering can provide powerful alternatives.

Of course, relationship opportunities are maximized when community members get to know one person with disabilities at a time, rather than having a group thrust upon them. Programs congregating individuals with developmental disabilities at the recycling center all at the same time will not provide the opportunity for real social inclusion. Substituting congregated community “volunteering” for a congregated day habilitation program will not promote community belonging. What is needed are ways for people with disabilities to volunteer as individuals.

### ***Contribution, Happiness and Satisfaction***

John Kennedy (“Ask not what your country can do for you, ask what you can do for your country”), Martin Luther King, Ghandi, and Mother Teresa all inspire us because they touch that part of us that longs to know we made a difference for others. We want to be a “point of light,” knowing we lit up life for someone else. Having such experiences is critical for self-esteem and happiness.

Freud has said that love and work are the cornerstones of our humanness. “Work” here does not necessarily mean a paid job, but that sense that we are doing something that makes a difference for others, that it is meaningful activity that contributes. One man with developmental disabilities who volunteered dusting books in a library said after his first night there, “The books were really dusty, they really needed me.” How many people with disabilities have that opportunity to authentically know and say, “They really needed me”? People with developmental disabilities often are on the receiving end of contribution. People without disabilities often report getting a great deal of satisfaction from volunteering for people with disabilities. When people with disabilities themselves have the opportunity to volunteer, they can receive those same benefits. The more opportunity they have to give, to contribute to others, the more personal satisfaction is possible.

Critical thinking regarding the volunteering situation is necessary to see whether people with disabilities are having those experiences. Simply “putting in time,” especially if one is not getting paid, is not sufficient. It makes a difference to find opportunities for individuals to contribute their unique gifts and talents (rather than volunteer opportunities anyone could fulfill), where others who are important to those individuals

make sure they are acknowledged and appreciated, and where they receive the satisfaction of knowing they were “needed.”

### **Developing Marketable Skills and Job Opportunities**

Volunteering provides many opportunities to learn and to practice skills that can be useful in paid employment. Most day habilitation programs across the country can probably provide examples of starting someone out in a volunteer situation that became a paid job. Of course, one of the things to beware of is that volunteering cannot substitute for work that should otherwise be paid. A useful gauge is whether non-disabled community members volunteer in that particular way; if they do, then it is also a legitimate volunteering opportunity for people with disabilities.

### **Networking**

A fact of life is that “who you know” affects most everything. For instance, about 70% of all jobs are obtained through personal contacts. People who get to know politicians and legislators can often get personal and individual requests honored. Volunteering in elected officials’ offices, chambers of commerce, and city, county and federal public administration offices can provide very fruitful networking opportunities. One man who joined the Sertoma Club (a community service organization with many business owners and professionals) networked with his fellow club members when he bought a home of his own – he knew an electrical contractor who helped with his wiring and an attorney who helped him with his deed.

### **Status and Reputation**

In any city or town in the country, examine the lives of the people considered the leading citizens. Almost invariably, everyone is involved in some form of volunteering. Actors and actresses, politicians, and corporate executives receive

huge acknowledgment and recognition for their “charity work,” the benefits they put on or attend, the work they do for a vast array of groups, and many for their own foundations. Even in smaller towns, the people considered the leading citizens are involved in charity balls, fundraising events for the local theatre or opera, and local service organizations. Kiwanis, Jaycees, Elks, Lions, Optimists, the Sertoma Club, and myriads of other “community service” groups (often with many of the leading business owners and “high-end” people in town) all volunteer to help with festivals, parades, clean-up and beautification efforts, and booster clubs. The involvement of people with developmental disabilities in these groups and efforts can stimulate more highly valued social roles, connecting with more highly esteemed people, and greater status. For individuals who have historically been in the most socially devalued roles, their volunteering can serve to shift their own view of themselves, as well as their community’s and the entire cultural view of people with disabilities.

### **Conclusion**

In conclusion, the activities undertaken to establish individualized, meaningful volunteer opportunities can be more than worth the effort. They can lead to expanded opportunities and multiplied benefits for the person with disabilities, communities, and the larger society.

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## **Where to Look for Volunteer Opportunities**

*Every community – large or small – has volunteer opportunities and needs. Below are some typical places where people volunteer, and where adults and youth with developmental disabilities may want to explore volunteer options:*

- Faith communities
- Youth-serving organizations
- Special celebrations (e.g., parades, Cinco de Mayo, Kwanzaa, city festivals)
- Civic and business groups
- Sports leagues and events
- Community beautification committees
- Libraries
- Schools (K-12, pre-school)
- Refugee/immigrant centers
- Nursing homes and hospitals
- Crisis services (e.g., homeless shelters, food banks, counseling centers)
- Arts organizations
- Charitable organizations
- Block clubs
- Park and recreation programs
- Literacy programs
- Historical societies and museums
- Organizational and agency boards
- Fundraisers (e.g. for organizations, communities, and individuals)
- Community gardens
- Food coops
- Nature centers
- Community access television
- Election activities (e.g. voter registration drives, candidate campaigns)
- Disaster relief efforts
- Advocacy and education organizations (e.g., disability, environmental, human and civil rights)
- Senior centers
- Student service and leadership groups
- Animal shelters, wildlife rehabilitation centers

# Improving Volunteer Options for Persons with Developmental Disabilities

by Helen Lowery

Volunteerism has many faces. A person can volunteer once on a particular project or they can volunteer for many projects over a lifetime. They may choose to work on one event annually or they may choose to volunteer on a weekly basis. They may serve through the types of local volunteer opportunities available in virtually every community, or they may provide extended service through Corporation for National Service programs such as AmeriCorps, AmeriCorps VISTA, Senior Volunteers, and Service Learning. All of these options are a perfect venue for people with developmental disabilities to have meaningful volunteer experiences, increase social activities with all people, and ultimately have a greater sense of belonging and contributing to the community in which they live.

Benefits of volunteerism to individuals with developmental disabilities are many. Among them are the opportunity to give. The role of "recipient of services" traditionally has been the role assigned to people with developmental disabilities. It is important that individuals with disabilities have the opportunity to be on the giving end of the equation, to feel the good that comes from helping others, and to learn to give support to others when they have a need. Another of the many benefits of volunteerism for persons with disabilities is the chance to take part in activities where they can develop more peer relationships and increase future opportunities. Many individuals with disabilities interact primarily with their families, the people who provide service, and others in the programs in which they participate. These relationships can clearly be significant and should be encouraged. However, outside of family members, people may not have freely given and chosen relationships. Volunteerism could be a way to increase the

opportunities for persons with developmental disabilities to form new friendships. Volunteerism offers an opportunity for continuity of friendships and relationships; a person can volunteer with the same group of people over time and learn about friendship as a different source of security, comfort and self-worth (The Arc, 1998).

While it is clear that individuals with disabilities have much to gain from volunteering, there are many barriers to participation. Among them are attitudinal barriers, programmatic barriers, and economic barriers.

## Attitudinal Barriers

The most common barriers are the attitudinal barriers that arise from the many myths about persons with disabilities that are based on ignorance. Among them are:

- Persons with mental retardation cannot learn volunteer jobs.
- Persons with developmental disabilities require too much training and supervision.
- Persons with developmental disabilities are unreliable and likely to cause injury to themselves or others.

One way to dispel the first myth is to realize that we have many service providers who are skilled in the basic principles of effective learning strategies for people with mental retardation. People with mental retardation learn most effectively when the instructional process is highly structured and direct. When supervisors offers this type of instruction, almost any skill can be learned.

There are concerns that individuals with developmental disabilities may require more training and supervision than the organization can support. In some cases, it does take people with disabilities longer to master the tasks asso-

ciated with a position. Supervisors or others may need to spend some extra time with these volunteers during the first few days or weeks. However, once they have learned the position, volunteers with disabilities have demonstrated effective performance. In my experience, this is not an issue because in most volunteer situations there are always at least two people working together. One innovative project, Project Success (funded by the Corporation for National Service), paired adolescents with cerebral palsy with adolescents without disabilities on all of its service learning activities. This strategy raised awareness of the capabilities of the adolescents with cerebral palsy, raised awareness to how much more alike adolescents are whether they have a disability or not, and fulfilled the need for partner assistance. In some cases, an attendant or a job coach may be a reasonable accommodation to be available to help the person. A job coach is a specialist who accompanies the individual with disabilities to the volunteer site to assist in the initial training period. The job coach may assist the volunteer in learning tasks or make recommendations to the supervisor of the project about suitable changes to the position to help accommodate the volunteer.

In regard to the third barrier, many people have the impression that individuals with developmental disabilities are unreliable and pose a risk to themselves or others. The President's Committee on Mental Retardation (1983) reports safety records on the job of employees with developmental disabilities to be equivalent to employees without disabilities. In addition, persons with developmental disabilities have as good or better attendance than many employees without disabilities. Individuals with disabilities do not present records of less reliability and safety than others.



## Programmatic Barriers

Organizations may hesitate to recruit and place volunteers with developmental disabilities because they are not sure they know how to accommodate their disability. Our world has become so litigious, that rather than make it more embracing of people with disabilities, people who direct volunteer projects and business are often more fearful of doing the “wrong” thing rather than taking what appears to be a risk to do the “right” thing. In each and every community, there is a world of resources in the disability community. There are people who will help organizations decide what are the best and most reasonable accommodations, help with site and programmatic accessibility, and help educate organization staff about disabilities and how to best work with individuals with a variety of disabilities. Also, the person with the disability can be a valuable resource for the organization; a person many times knows best what they need because they have been living with this disability all of their life.

## Economic Barriers

Another barrier can be the economic arrangements that conflict with disability income. In AmeriCorps, for instance, many participants receive a monthly living allowance. Because of some confusion in the way the National Community Trust Act was written, people with disabilities who serve in AmeriCorps must count their living allowance as earned income. For some people, this causes problems in that it can lead to the loss of some benefits. I cannot stress “in some cases” enough. What I recommend to individuals with disabilities who are thinking about applying for an AmeriCorps position and who receive SSI is to consult their Social Security Office first or Access AmeriCorps and see if there will be such an impact on their government assistance. Just because their money is impacted it does not prohibit them from serving. They may want to take a part-time position or an education-award position. AmeriCorps is

about more than making the living allowance. For people with developmental disabilities it would be about service, inclusion, education, skill building, and relationships. But everyone should be knowledgeable about the financial impact before they start.

Another economic barrier emerges from the low incomes that many individual with disabilities have. Limited resources can affect things such as access to transportation to volunteer activities, and the ability to purchase uniforms or other required volunteer items and equipment. Organizations must look at any volunteer requirements that involve expenditures on the part of volunteers, and identify options to remove economic barriers to participation.

## Conclusion

Persons with developmental disabilities may have low involvement in community service and volunteerism because program planners have assumed they could not or would not want to be involved. However, attention should be focused on changing the environment to accommodate all people rather than attending to one person’s disability or inability to participate. As the environment becomes friendlier and more accommodating, it will not be a question of whether persons with disabilities will be able to contribute. It will more be a question of where can their abilities be best utilized.

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## Improving Inclusion in Volunteer Programs

*Below are steps that organizations can take to ensure that their doors are open to volunteers with developmental disabilities. For additional information or assistance related to any of these items, local chapters of disability organizations such as Arc, Easter Seals, or United Cerebral Palsy can be valuable resources, as can disability agencies and services.*

- *Evaluate your program's accessibility on the physical, programmatic, attitudinal, and economic levels.*
- *Be familiar with your obligations under disability-related laws.*
- *Include as a part of your volunteer and staff training a section on disability awareness and sensitivity.*
- *Ensure that your volunteer or service positions have clear position descriptions stating the essential functions of the positions.*
- *Ensure that your application process and all forms are accessible.*
- *Actively recruit qualified persons with disabilities by sending information about volunteer positions to local disability agencies. Add an inclusive statement to all of your recruitment materials (e.g. "Individuals with disabilities are encouraged to apply").*
- *Make the interview about ability and not disability.*
- *Be prepared to coordinate reasonable accommodation requests. Determine what resources are available to implement accommodations before anyone ever makes a request.*

Adapted with permission from materials written by Helen Lowery and Amy Desenberg-Wines of Disability Consulting, L.C., Norwalk, IA 505/981-4113 or aw411@earthlink.net

# Disability Agencies Supporting Volunteers

by Pam Walker

There are multiple reasons why people with developmental disabilities seek volunteer work. It could be to meet new people, pursue an interest, have a sense of contributing to a cause or a community, gain skills or to fill time. Because there is still a shortage of paid and full-time work options for people with developmental disabilities, volunteer work is something they do in addition to, instead of, or while looking for paid work that contributes to a meaningful day. Some find their own opportunities to volunteer and participate individually. Others need assistance from staff of vocational and residential support agencies, and may volunteer with agency staff. Whatever the reasons and ways in which people with developmental disabilities volunteer, such involvement is a source of satisfaction for many.

Agencies that are creating more individualized volunteer opportunities, on a person-by-person basis rather than using a group approach, can offer individuals greater opportunities to participate in volunteer activities that match their personal interests and goals, and enable them to get to know other volunteers and be more included in the community. Some agencies that offer vocational and day habilitation services have broadened the scope of their supports to include supporting people in volunteer work situations (Fratangelo, Olney, & Lehr, 2000; Hall & Walker, 1997; Walker, 1998). For example, Onondaga Community Living, in Syracuse, New York, uses day habilitation funds to support people in vocationally-oriented volunteer positions. This includes people who “either have part-time jobs and want more community involvement, or have not chosen supported employment for a variety of reasons. Some people... are not sure of what they like or are good at. Others care little about money, but want skills and experiences. Some individuals have tried numerous supported employment jobs but have not

found their niche...” (Fratangelo, Olney, & Lehr, 2000, p. 78). People volunteer at places such as a preschool, a peace organization, the library, and a nature center. Some of the volunteer jobs have turned into paid employment.

People have also been assisted in volunteer positions through residential support agencies. This is often as part of a broader effort to help people pursue interests as well as to assist them in expanding relationships and sense of community membership (e.g., Amado, 1993; Johnson, 1985; Reidy, 1993). Based on such efforts, much has been written about strategies and lessons related to promoting meaningful community involvement. Some tips include:

- Connections and opportunities should be made individually, versus for a grouping of people, based on personal interest and choice.
- Agencies should be prepared to offer whatever levels and types of support a person needs – ranging from getting actively involved with the person over the long term, to stepping back and getting out of the way.
- Place is important – focus should not just be on finding any place “in the community,” but on finding places where people feel comfortable and welcome, feel a sense of connection/belonging, have a valued role, and have social interaction opportunities.
- Efforts should be made to promote personal relationships and “natural supports”; this can help prevent the loss of a volunteer opportunity or other community connection if an agency support person leaves.

Just as agencies have difficulty supporting people in paid work, so, too, they experience limited resources for supporting people to participate in meaningful, individualized volunteer opportunities. Thus, in addition to initiatives generated by the service system to promote volunteerism and other

forms of community involvement, it makes sense to start connecting with and building on local, generic initiatives that promote community participation in general. One resource to assist agencies in this effort is, *Involving All Neighbors: Building Inclusive Communities in Seattle* (Carlson, 2000). It describes a collaboration between the Washington State Division of Developmental Disabilities and the Seattle Department of Neighborhoods, as part of an initiative of the Department of Neighborhoods. The manual provides examples of many different types of volunteer community involvement as well as lessons learned through the collaboration, and it concludes with the reflection that these efforts were “not just about building neighborhood inclusion for persons with developmental disabilities. They are about building neighborhood inclusion for everyone” (Carlson, 2000).

Volunteerism by people with developmental disabilities can be part of a rounded life, and support for it by disability service providers is important. When it includes diverse individuals, it benefits not just the volunteers, but also their neighborhoods and communities.

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# Finding a Good Match: Questions for Volunteers and Organizations to Ask

by Jill Murray

People who have disability labels have skills, perspectives, and experience that they can use to contribute in meaningful ways to their communities through volunteering. For volunteering to be a positive experience, there must be a good match between the person and the volunteer position. Below are some questions that individuals with disabilities can ask themselves and the organizations as they search for the right volunteer activities for them, and questions that organizations can ask as they assess their own response to a volunteer with a disability.

## Questions for Volunteers to Ask Themselves

- Do I want to volunteer for something that I am already interested in? Or do I want to learn something new?
- Do I believe my work has value?
- Will I be able to make a meaningful contribution through this volunteer work? Will it be recognized?
- Why do I want to volunteer my time instead of getting paid?
- Do I have time to offer? What is the time commitment and what is the length of service?
- Do I support the organization's goals?
- Do I want to volunteer with this organization because it is doing great things? Or because I want to change it?
- What will I learn through this volunteer experience?
- Do I want to volunteer with a disability-related agency?
- Do I want to work where I can educate others about issues of people with disabilities?

- Do I want to find a place that will link me to a new area or group?
- Does the organization ever hire anyone with a developmental disability for paid employment?

## Questions for Volunteers to Ask Organizations

- Will you tell me what to expect in this volunteer position?
- Is this real work, with responsibilities and accountability?
- Does your staff believe I am a valuable member of their team?
- What experience does your staff have working with people with support needs?
- If I have problems with my duties, my supervisor, or support issues, who is my contact?
- Who would listen to me if I had ideas or shared perspectives on how the organization could improve?
- Will you give me the supports I need to do the job you expect?
- Have others with disabilities volunteered here before?
- Can I call a past volunteer to get a reference?
- If this position is not the best match for me, how should I tell you?
- If you think I could do a better job, how will you tell me?

## Questions for Organizations to Ask Themselves

- Why are we accepting this person as a volunteer?

- Do we truly believe this person has something to offer?
- How will we train this person and set up clear expectations for their work?
- Is the staff that will be the main contact prepared to respect this individual's unique support needs, including alternative communication, transportation, mobility, coaching, and personal assistance needs?
- How will we respond if this volunteer does not fulfill the responsibilities of the position?
- How will we set up communication between staff about support needs of the individual?
- Are we willing to problem-solve with the volunteer in an honest manner?
- If this volunteer turns out to be productive and effective, are there any options to hire them?

Hopefully, asking these questions will help create environments where individuals with disabilities who wish to volunteer can follow the advice of self-advocates from Oregon: "Find out what is out there to get involved in. Then pick something you really believe in and give it all you have."

Adapted with permission from:

Gobel, S. and Flynn, J. (1995). *Not another board meeting: Guides to building inclusive decision-making groups*. Salem, OR: Oregon Developmental Disabilities Council.

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## Preparing Youth With Disabilities for Volunteer Service as Adults

by John G. Smith, Ann L. Mavis, and Julia Washenberger

Individuals engaging in voluntary service have much to offer the community, and the experience of volunteering has much to offer those who provide such service. The youth of America have long engaged in community service activities through churches, scouting, and a myriad of other youth organizations, as well as on their own or with their families. With appropriate opportunities and support as necessary, youth and young adults with disabilities can join their peers in contributing to their communities and enriching their own lives by participation in voluntary service.

*As youth have success in being of real service to others, they will learn that their efforts matter, and that they, as youth, matter to the larger community.*

Despite improvements in special education services for transition-aged youth with disabilities, they continue to have great difficulty in accessing postsecondary educational programs, finding meaningful, if any, employment, and becoming active and visible members of their communities following high school (Johnson, D.R., et.al., 1996). Youth and young adults with disabilities need encouragement and support to become involved in all types of activities that will foster their success in later life. Involvement in service activities in the communities where they live has the potential to provide many benefits, both to youth with disabilities and to their communities. To ensure such benefits occur for

both parties however, it is important that service activities be chosen and arranged to match the capacities, support needs, and interests of each individual. This is the key to ensuring that volunteer and service activities truly support youth in making a successful transition to adult life, while also allowing the communities where they live to benefit from their efforts and gifts.

There are several ways for youth with disabilities to become connected to and have successful experiences with community service activities. One is to include activities of community service as part of a student's educational plan. According to the Individuals with Disabilities Education Act (United States Code, Chapter 33), the general purpose of special education services is to prepare youth with disabilities for "employment and independent living." The Act further stipulates that this broad end should be pursued in the context of each student's unique strengths, interests, and needs for support. As students with disabilities become adolescents and young adults, it is good practice for their education plan to become increasingly focused on their post-graduation plans. For youth planning to enter employment upon graduation from high school, including opportunities to be of service to the community as part of the school day can provide new avenues to pursue interests, develop skills, and gather experiences that will be readily useful in becoming employed as adults. In fact, activities of community service may provide a more useful experience in developing skills that will lead to employment of personal interest for a particular student than the limited range of paid work experiences many school transition programs are able to generate.

Eccles (2001) and McLaughlin (2000) have studied youth and the organizations that serve them for several years.

As a result of this research, they have identified several characteristics of effective youth service organizations. While neither McLaughlin nor Eccles focused on youth with disabilities in particular, many of their shared conclusions describe the characteristics of other "mainstream" programs that have been successful in the inclusion of persons with disabilities. As community service activities take on the following characteristics, they will also serve as effective development activities for youth with disabilities, and support these youth as they prepare to assume meaningful lives as adults:

- **Community service activities need to offer opportunities for skill development.** According to McLaughlin (2000), youth most value those programs that offer challenges, call on youth to use their skills, have a clear focus, utilize multiple teachers, and include an "embedded curriculum." The best community service opportunities for youth with disabilities will be those that are able to recognize and respond to their diverse talents, skills, and interests, and are committed to helping youth develop valued skills that will lead to additional opportunities, including paid work positions.
- **Community service activities for youth with disabilities need to support feelings of self-efficacy, and "mattering."** Eccles (2001) has noted that a critical element in activities focused on youth development is "youth-empowerment and responsibility-taking" through offering youth meaningful challenges. As youth have success in being of real service to others, they will learn that their efforts matter, and more importantly, that they, as youth, matter to the larger community. McLaughlin (2000) adds

that community activities can assist youth to develop this sense of self-efficacy, as programs build in cycles allowing youth to practice skills, perform, and then receive ongoing feedback and recognition for their efforts. Community service activities that provide such support to youth can be an incredibly powerful force in helping youth with disabilities to see themselves as valued members of their communities, to develop confidence in their abilities to “make a difference” to others, and to build attitudes that will fuel a personal sense of self-determination.

*Youth and young adulthood is a time when it is important to build the relationships and develop the skills that will translate into success in adult life.*

- **Community service activities need to provide youth with disabilities the support they need to be successful.** Both Eccles (2001) and McLaughlin (2000) emphasize that all youth need environments that provide them with a sense of belonging, are warm and caring, include adults who are genuine in their concern for youth, and consistently afford emotional safety for everyone involved. This type of support is of particular importance to many youth with disabilities. Organizations interested in including youth with disabilities in service activities need to ensure a service environment that is healthy and safe, have clear rules and boundaries, and provide an age-appropriate structure that promotes mutual support and a “pro-social” environment. In addition, community service programs need to be committed to providing personal at-

tention to *all* volunteers, and be flexible in shaping the experience to meet the needs and goals of each volunteer. For youth with disabilities, this may include coordinating the volunteer experience with the youth's school program and his/her family, who each may have expert knowledge of a youth's interests and the support needs that will make it possible to be successful in a volunteer experience.

Youth and young adulthood is a time when it is important to build the relationships and develop the skills that will translate into success in adult life. Instilling an attitude that values service to the community, while developing useful skills and a sense of making a difference to the community, cannot be underestimated in contributing to successful adult lives for all youth, but especially for youth with disabilities. Schools, community organizations, governmental agencies, parents, and youth themselves need to become aware of the opportunities available for youth with disabilities to participate in volunteer activities, and to make the commitment to support the participation of youth with disabilities in these activities. In this way we will develop a system where everyone benefits, and where youth with disabilities will feel valued and will contribute to their communities.

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## Service Learning: Increasing Youth Involvement

*Service learning is applying classroom learning to out-of-classroom activities that meet genuine community needs. Students gain new skills while helping others who need them. They discover that learning doesn't only happen inside classrooms. They also realize that they are valuable members of society who can make the world a better place. Some activities are based in the communities. They include programs such as Big Brothers/Big Sisters and Camp Fire Boys and Girls. Others are based in the schools and are made part of the regular curriculum. Three of the many exciting activities students have done with service learning in Minnesota are:*

- *Students at Northeast Middle School in Minneapolis designed and painted an outdoor mural to brighten their school's courtyard. This is part of a larger project to build a "Gathering Place" for members of the school and community to meet.*
- *At Northland High School in Remer, students built a playground for their community.*
- *In Waconia, middle and high school students in a program for students at-risk run a farm where, among other activities, they help young children with disabilities ride the horses as part of We Can Ride, a therapeutic horseback-riding program for people with disabilities.*

*Interested in seeing service learning at your school? Talk to the teachers, the principal, and the P.T.A. Funding and technical assistance are available. For more information contact the National Youth Leadership Council in St. Paul, Minnesota, 651/631-3672 • <http://www.nylc.org>.*

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## Disability Agencies and Cultural Communities: Working Together to Support Volunteers

by Cheska Komissar, Maria Paiewonsky, Debra Hart and Rooshey Hasnain

Jiang-man had always loved the annual Chinese Boat Festival. She would brighten up the moment someone mentioned that it was getting close. For weeks afterward she was only interested in recounting the day's occurrences. While she was in school, there was so much focus on her multiple disabilities, that her cultural interests were never really part of her education. It was not until middle age, after her parents passed away, that Jiang-man's service coordinator thought about all the planning and work that must go into the festival, and the possibility that Jiang-man could be involved. After making inquiries, the coordinator discovered that most of this spectacular event was carried out by volunteers. Jiang-man joined them.

There's an important lesson in this story: For years Jiang-man missed an opportunity to participate in her cultural community because no one thought of it. We, as disability service providers, primarily represent white, middle class values and consequently may not think of volunteer opportunities that build on the ethnic and cultural identities of those we serve. One might wonder why her parents did not suggest the Chinese Boat Festival as a place where she could volunteer. But again, that is the thinking of "our" culture. In her's, educators, social workers, and doctors are respected beyond any other profession – if they did not suggest it, it would not be her parents' place to do so. It is necessary to understand such contrasts between the cultures and values of those providing services to persons with disabilities, and those of the numerous groups that continue to enrich the fabric of our country.

### Addressing Cultural Connections

Working with individuals from diverse cultures can be challenging for many disability service agencies because it is

an area in which they are often not knowledgeable or experienced. Yet, many minority cultural organizations are grassroots organizations that are thrilled to assist someone from their community in any way they can, regardless of ability, including assisting them to become more involved in the community through volunteer activities.

Over the years, the Institute for Community Inclusion (ICI) at the University of Massachusetts and Boston Children's Hospital has learned a great deal about how people with disabilities choose to enter into volunteering, how people from different cultures regard and can participate in volunteering, and how service providers can assist them in reaching their dreams. The following are five lessons we have learned that may be of use to disability service providers seeking to work with and within cultural communities:

- **Identify the gatekeepers.** These are the leaders of the cultural community. They can be clergy or lay leaders, social agency or cultural organization professionals. They are the people who have "one foot in each world" – belonging to the minority group, yet understanding working across many communities and systems. Gatekeepers are crucial in helping service professionals to understand cultural differences and nuances. Further, they can assist providers in talking to families, identifying opportunities for individuals, and creating new opportunities where none previously existed.
- **Understand that "disability services" may be a foreign notion to many cultures.** Often minority cultural organizations say that they do not serve individuals with disabilities. Yet when the conversation is continued, it may be found that their

initial response is only an misunderstanding of the word "disability." For example, some do not understand that mental health issues may be considered disabilities. Depression and post-traumatic stress disorder are common for individuals who come into this country as refugees (vs. immigrants – who have come here because they want to live in America instead of because they needed to leave their country). Further, the meaning of the word "disability" is not necessarily translatable. Medical terms (e.g., autism, PDD) are also difficult to render into another language. Even common terms such as "developmental disability" or "mental retardation" may not translate. For example, in Urdu (spoken in Pakistan), "Pagal" is the closest word to mental retardation, yet it actually translates as "crazy." Further, in Pakistan, a daughter who can serve tea to the other villagers is not seen as having a disability. Moving to this country she is tested and is found to have moderate to severe mental retardation. The family may not even understand the diagnosis or its implications here.

- **Understand the connotations the type of volunteer setting may have.** For example, in some cultures, working in a hospital is very prestigious. In other cultures, working in the sterile setting of a hospital where traditional healing is not practiced may be seen as demeaning – not something someone would volunteer to do. In fact, serving people in general can be seen as good or bad depending on the culture.
- **Recognize that in some cultures, any connection to government may be a barrier.** First, individuals needing and/or offering services may not be in this country legally, so they

may fear any involvement with a formal agency (especially if it is state-operated). Second, they may have a lingering fear from their own home governments. The assistance of a gatekeeper may be needed to help work with families and groups.

- **Be aware that in many cultures the sense of family and community takes precedence over everything.** This means that volunteer jobs may need to be in the cultural community. Typical volunteer activities such as visiting nursing homes, fundraising or cleaning up the park may not be available within the ethnic community. Further, depending on the culture, the notion of “volunteer jobs” may not even exist. It may be seen as natural to care for an elderly neighbor or family member; neighborhood playgrounds are kept clean through individual effort. You may need to be more imaginative in finding or creating a volunteer position. Or you may find that your best bet lies somewhere unexpected. For example, in one Latino community, a small organization was responsible for providing counseling to troubled youth. On the surface, the sole employee of the agency really did not do his job well – he held nothing resembling any “counseling” session any ICI employee had ever encountered. But what he did do well was to mobilize the youth of the community in a huge volunteer effort to offer an annual Latino Pride day. On occasion, we just need to learn to take what is good out of a situation.

### Further Recommendations

Obviously, when assisting people to find volunteer positions it is most important to determine their interests and experiences relating to volunteering and then find or develop appropriate matches in the community. For example, consider the experience of Ruan. Ruan is a young woman with developmental delays and a father who has multiple sclerosis. Her

family is very involved in fundraising for the Multiple Sclerosis Society. It is her personal experience with her father that has led to her annual involvement at a bicycle race fundraiser in Martha's Vineyard. Although she volunteers only once a year, the effect of the day is long lasting as is evidenced by her enthusiasm each time she describes it. Further, because she wants to be a country western singer and she knows that her favorite group (Diamond Rio) does a lot of volunteer work, she has a deep-seated desire to volunteer. Ruan is also the recipient of volunteering in the form of a “best buddy.” Since she is getting older now, she has become interested in evolving into the kind of person who provides this type of service to someone else instead of always remaining a recipient. To this end, she has taken a volunteer position at a summer camp where she can take the part of a “big sister” to some of the campers. Because of her personal life experiences, Ruan has chosen these specific volunteer outlets.

As human service providers, we can assist people from diverse ethnic and cultural backgrounds to participate in their cultural communities and the broader community through volunteer efforts. To do this we must forge connections not only with the gatekeepers and organizations of cultural minority communities, but also with organizations which assist people in arriving in this country (e.g., Immigration and Naturalization Services, local refugee services agencies). Most importantly, it is crucial to remember that each service provider has his or her own cultural and class biases and limitations, and we must continually strive to broaden our horizons in our search for what is possible.

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## Finding Her Niche: Angela's Story

*Angela has always wanted to play cards, but has had difficulty finding a group of people in her community who play on a regular basis. At a meeting with the agency providing her with respite care, Angela suggested that she might volunteer at a local nursing home as an outlet for her card playing. Angela now not only plays cards with the people that live there, but is a valued and regular volunteer. She describes it this way –*

*“I volunteer in a nursing home. I do the cards... we play cards. I call the cards out. Like I say, ‘Ace of Hearts’ or ‘Ace of Spades.’ Like that. I do that from six to eight, once a week, every Thursday. We play [games] like matching games. They have to match to be able to get their cards into the pile. My mother's grandmother lives at the nursing home so I thought it would be a good place to volunteer. I know they play cards. There's a girl named Audrey there. She is the boss, and she is in charge of the residents – getting them through their suppers, lunches, breakfasts, and stuff like that. I talked to Audrey, the one who is in charge, and I asked for the job. It was my idea. I am basically the activity lady. I play cards and sometimes watch “Wheel of Fortune” with them. They love me there. They even have dinners for us maybe every year – for the people who work there. I get to go to that too. They love that I come in every Thursday and help out. I sometimes bring the residents back to their rooms. I love it. It gives me something to do on Thursday nights. It gives me a chance to know the residents better. I get to see the residents each time when I come in. It makes me happy to see them every Thursday.”*

Contributed by Angela and by Cheska Komissar, Institute for Community Inclusion, Boston.

## Why Volunteering Matters to Me

by James Meadours

I am the chairperson of Self Advocates Becoming Empowered (SABE), and the Self-Advocacy Coordinator of the Louisiana Self-Advocacy project. My position with SABE is volunteer. SABE is the national self-advocacy organization, and I have been on its board since 1994, when I was elected as a regional representative. My job in Louisiana is a paid position, and my responsibilities are to start local chapters around the state, do training, and be people's advocate, as needed.

I want to share my thoughts and experiences as a volunteer. My very first volunteer job was when I lived in Texas and I helped a group of kids (ages 6-8)

The next year we moved to Oklahoma, and because of the move, I couldn't work with the team again.

I first heard about the Corporation for National Service (which runs VISTA and AmeriCorps) later on when I was in high school and working at a sheltered workshop part-time in Tulsa. I wanted to be a Peace Corps volunteer. I didn't really pursue that. Instead, I was moved to a group home from my parents' home, and I worked full-time at the sheltered workshop. My only volunteer work at that time was at church, where I was an usher on Sundays. Then one day I learned about what was then called Tulsa Self-Advocacy Committee in the Tulsa ARC newsletter. I wanted to change the address on my voting card to the group home address, and I decided to go to a meeting because the program that night was on voter registration. I went and got my voting card changed. I didn't go to any more meetings until a year later. I saw the advisor, Michelle Hoffman, at the fair and she invited me back. I told her I wanted to go to the meetings, but the group home didn't want to provide transportation. She said she would give me a ride, and she did that for every meeting after that.

Michelle and I became good friends, and I later became president of the local group. I started a job in a clothing store, and I volunteered my time with People First, going with Michelle to other towns and helping to start groups. My brother Joe lived in Broken Arrow, so when a group started there I got him involved. When I was doing that volunteer work, I didn't have as much flexibility with my time as I wanted because I lived in the group home and worked at the clothing job. A year after I started at the clothing store, I moved out of the group home and into my own place. Two years after that, I became a VISTA volunteer with People First.

To make a long story short, I've come a long way, and it is because of the vol-

unteer work I did. That work gave me confidence and let me believe in myself, and it taught me skills that I have needed ever since. My experiences have convinced me that it is really important



for young people with disabilities to have opportunities to volunteer. Volunteering can help people believe in themselves, gain the confidence to do things others may think they can't do, and to show people that people with disabilities can volunteer, no matter whether it's a local YMCA, local food bank, a library, or a baseball team. We can contribute to our communities. Doing volunteer work when one is young helps to keep a person from getting stuck in the social service world. It can also help people learn leadership skills and other kinds of skills. It's easy for us who have disabilities to accept the view of the world that we are incapable, and to take that for granted. Getting involved in volunteer work helps us to get away from that stereotype. I hope people will encourage young people to have these opportunities, because they are the next generation of leaders of the self-advocacy movement.

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***It's easy for us who have disabilities to accept the view of the world that we are incapable. Getting involved in volunteer work helps us to get away from that stereotype.***

on a baseball team. My friend's family asked me to one of the team's practices, and I asked if I could volunteer. I was in special education, and this was a team of typical kids, but they accepted me. My job was to be behind the scenes giving the kids encouragement by calling to them things like "You can do it! You can hit the ball!" The team won first place in their league and then first place in the tournament. This was the first team that had done that in one year. At the end of the year the team had a big picnic and gave me a plaque that said I was an honorary team member. It made me feel really good about myself to help others and to be recognized, especially since the relationship between me and my parents was a little rocky at that time.



## ***Singing for Social Justice: The Syracuse Community Choir***

by Pam Walker

The Syracuse Community Choir is a “community” of people who gather to sing songs of peace and social justice. They rehearse weekly, and perform several times a year at concerts and various community events, vigils, rallies, and celebrations. The membership of the choir includes a wide variety of people of varying ages, racial and ethnic backgrounds, and abilities. What brings them together is an interest in music, a desire to work for social justice, and a quest for community connections.

The involvement of a diversity of people, including a few members who have severe and multiple impairments, is made possible by a number of factors. First, it is due to the vision of the choir’s founder and director, Karen Mihalyi. Part of her vision for the choir is creating an “inclusive community.” She traces this, in part, to her childhood in a small town where everyone was part of the community. She comments, “This does not mean that there was no prejudice...but at least people met up with each other.” She adds, “To create community today is difficult – so many forces work against it – but people are hungry for community.”

Second, the diversity of the choir is intentional, not accidental. It happens as the result of a few things: a) intentionally inviting a diversity of people to join; b) creating a welcoming environment where people feel comfortable, listened to, and know that their presence is valued; c) singing a wide range of music that gives voice to people’s issues; and d) making the choir accessible in a wide variety of ways (e.g., using wheelchair accessible spaces; offering music in large print and Braille; having child care available at concerts and rehearsals; having sign language interpreters; helping with transportation, etc.).

Over the years, the choir has had to address certain issues raised by the par-

ticipation of people who are supported by human service agencies. For example, some agencies initially brought groups of people to join the choir, rather than approaching it on a more individualized basis. Some agencies have assisted people to come to rehearsals for a specific concert, but then not made an effort to assist the person to participate in the concert itself. To enhance the participation of individuals with disabilities who are supported by agencies, the choir attempts to establish a collaborative relationship with the agencies.

Building inclusive community is hard and sometimes uncomfortable work, requiring long-term commitment. Connections between people who have had significantly different life experiences do not necessarily occur quickly. Over time, however, opportunities to be together and share experiences help people get to know one another on a personal level and to both see commonalities and appreciate differences. This, in turn, helps to foster relationships and a sense of community. As Karen sees it, building inclusive community with people with disabilities is the same as for all people: “It has to begin with relationships – which come from meeting each other, knowing each other, hearing each other, learning about each other. We have to spend time together to get to know each other.” Through its music, the choir sings about issues of peace, social justice, and equality; and through its example, the choir promotes both the vision and reality of inclusion.

### ***Danielle’s Story***

Danielle describes herself as a person who likes to keep busy. “I hate sitting home,” she says. One way she keeps busy is through doing volunteer work, both as a teacher’s assistant for the children’s Sunday school class at her

neighborhood church and as a choir member and board member for the Syracuse Community Choir.

When she first joined the choir, Danielle lived in a family care setting across town. She took Call-A-Bus to choir rehearsals and performances until the choir was able to find someone to

***Through its music, the choir sings about issues of peace, social justice, and equality; and through its example, the choir promotes both the vision and reality of inclusion.***

give her a ride. Soon, she moved from the family care home into a group home just two blocks from the community center where the choir rehearses. Since she has difficulty walking, she still gets a ride from choir members. Danielle reflects on her nervousness when she first joined the choir: “I didn’t know people and I was afraid people would laugh at me.” She also had difficulty with the notes on the music sheets: they were too small for her to read easily. After she raised this issue, she found out that the choir had large-print copies of its music available, which benefits a number of other people besides her.

After awhile, Danielle started to get to know some people in the choir and began to feel more comfortable there. Some of the people she has gotten to know through choir live in her neighborhood, and she sees them at other community places and events. One, in particular, has become a close friend.

Around the same time that she joined

*[Walker continued on page 27]*

## ***Lives, Not Programs: The Option Quest Philosophy***

by Frances Curley

Community Options, Inc. is a national non-profit agency that provides community-based residential and employment supports to individuals with disabilities. Incorporated in 1989, we now support over 1300 people in 10 states and the District of Columbia. Our philosophy is that all individuals should have the op-

***When most people think about “volunteers” and “people with disabilities” they think that people with disabilities need volunteers. When you turn this around and offer individuals with disabilities the opportunity to be volunteers and help others, the rewards for all involved are endless.***

portunities to live, work, play and grow in their communities of choice with the individuals they choose to be with. In other words, just take out the words “with disabilities” and refer to people. Consider the following. When someone asks, “What do people with disabilities do during the day?” there are three traditional answers to the question: get a job through supported employment, attend a day program or sit at home and do nothing. However, if you ask the question “What do people do during the day?” the options increase dramatically. People work part-time or full-time, volunteer, attend classes, participate in clubs, participate in civic organizations,

and the list goes on and on. It is the same list of options for people with black hair, people with blue eyes, people over six feet tall, and people with disabilities. The difference is that people with disabilities traditionally have needed “programs” while everyone else developed “lives.”

We advocate for “lives, not programs” and to that end developed the concept of Option Quest. Option Quest encompasses all the things that “people” do during the day. It is an opportunity for the individuals that we support in the community to have a broad range of experiences and choose the pieces they want to build their lives. Volunteerism has been a strong component of Option Quest.

When most people think about “volunteers” and “people with disabilities” they think that people with disabilities need volunteers. But when you turn this around and offer individuals the opportunity to be volunteers and help others, the rewards for all involved are endless. Through Option Quest we have developed volunteer opportunities at a wide range of locations with a wide range of job responsibilities. Locations include hospitals, nursing homes, libraries, day care centers, animal shelters, county parks, non-profit organizations (like the American Lung Association), schools, and churches – all based in the local community. Job responsibilities include serving food; assisting with recreational activities; reading stories to children; feeding, grooming and walking animals; beautifying parks; collating mailings; just being someone to talk to; and the list continues.

What is the value of volunteerism for an individual with a disability? The same as for everyone else. The greatest value is that of helping someone else. One of the first individuals Community Options helped to find volunteer work

stated, “This is the first time I have helped someone else!” It’s the “feel good” factor, and you can’t put a monetary value on it. It is priceless.

For some individuals volunteerism is a first step in the world of work. Being responsible for being there on time and completing the tasks at hand are skills needed in any job. It is an opportunity to build confidence and self-esteem. People appreciate that you are there. It is also an opportunity to try out a variety of jobs at a variety of locations. People can identify what they like to do and what they don’t like to do, where they want to work and where they don’t want to work, what they are good at and what they have to work on.

***There is a large untapped resource of dedicated, hard working, friendly volunteers in every community. Some of these people have disabilities. But more importantly, they have abilities.***

Many volunteer opportunities are at locations that also offer paid job opportunities. Being visible in the workforce and showing one’s abilities has led to paid job offers. The question sometimes arises, “When should a person with disabilities get paid and when can they volunteer?” This question usually is raised for good reasons. People don’t want to exploit individuals with disabilities. Again, the answer to this is defined by society just like it is for everyone else. I don’t know of any people that have “vol-

unteered" at a major for-profit corporation, the post office or McDonalds. People do volunteer at hospitals, parks, and churches. But people are also paid at those locations. A person with a disability shouldn't volunteer at a job that someone else would get paid to do. Likewise, he or she shouldn't get paid to do a job that someone else volunteers at. It's the same for everyone else.

However, sometimes a volunteer position can change into a paid position, as was the case with two young women in Passaic County, New Jersey. They were both volunteering at a local animal shelter. The owner utilized only volunteers at that time. Both of these women loved their jobs. They worked hard and made a significant difference for the owner. Because of this the owner offered them paid part-time positions. They were so good at their jobs that the owner was able to focus on other aspects of the business and was in the position to offer paid positions. Her words were, "I never had anyone before that worked so hard."

As part of Option Quest we work to find opportunities for individuals within or close to their local communities. They are seen every day by their neighbors as "individuals with abilities." They have a value to their communities, meet people, and make friends. They build their personal circles of friends to include people that have common interests, values, skills and dreams because they are spending time with people based on their abilities, not their disabilities. Consider spending every day at the same location with the same group of other people who have the same "inabilities" that you do. That's what has happened to people with disabilities for a long time, and still does because of the parameters of "programs."

If you help someone build a life instead of trying to fit him or her into a program, everyone wins. This was the case at the Northern New Jersey office of the American Lung Association (ALA). This office serves a very densely populated area and only had three paid employees. Every time they had a mailing to send out, brochures to fold or filing to

do, their other duties came to a halt. We arranged for several individuals to volunteer at their office every day to assist with these tasks. The volunteers gained great satisfaction from their work and the ALA office was able to reach out to more people in their community. Volunteerism is a successful way for someone to enter the community offering something instead of asking for something. There is pride in a job well done, in feeling that you have helped someone and that you contributed to your community or society.

In 1995, we transitioned a day program, previously run by the state, into community-based employment opportunities, including some entrepreneurial businesses. One of the businesses developed is Community Volunteer Connections (CVC). Through CVC, volunteers are dispatched daily to local organizations; some are regular assignments, some are seasonal and some are as needed. CVC has become a welcome resource to the community and an opportunity for individuals who previously attended a segregated day program to work in their communities alongside their neighbors.

There is a large untapped resource of hard working, dedicated, friendly volunteers in every community. They may be sitting in a day program or at home doing nothing. They may also be working and looking for something to do in the evenings or on the weekends. Some of these people have disabilities. But more importantly, they have abilities. John Garino is one of these people (see sidebar). John is one of these people now being recognized within his community for his abilities, not his disabilities. The challenge to everyone who reads this is to help someone like John build a life in his or her community. Volunteerism is a great place to start!

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## ***Caring for Others: John's Story***

*My name is John Garino. I volunteer at the Little Sisters of the Poor in Totowa, New Jersey. Little Sisters of the Poor is a nursing home run by the nuns from the Catholic church. I volunteered there from 1993-1997 and came back again in 2001. I chose to volunteer at the Little Sisters of the Poor because I was familiar with the people and other volunteers there. I participate in many church functions. I like to be around Fr. Doyle and the others. I also attend mass twice a week.*

*When I volunteer I get there around 10:00 a.m. and stay until 2:00 p.m. When I arrive I go to the break room and have a cup of coffee with a snack with some of the residents. I then go downstairs to the laundry room and fold towels and put them in order by color. I also fold sheets and pillowcases and separate them into colors. The other thing I enjoy doing is to go visit a woman on the second floor. She is one of the ladies who resides there. When I go to visit we sit down and just talk about our families or what else is going on that day. I really like spending time with her. I enjoy her friendship as well as she enjoys mine.*

*Volunteering is very fulfilling for me. I am able to help other people and meet a lot of new friends. And it gives me the confidence to keep a competitive job at an A&P supermarket as a bagger.*



## ***“I Just Go and Learn and Give”: Self-Advocates Serving on Boards in Vermont***

*by Johnette Hartnett and Phil Smith*

“You can make a difference on the board.” That’s what self-advocate Patty Grassette says about her role on the board of directors for the agency that provides her services and supports. “It started when a friend who was head of the agency asked me to be on the board and help things out.” Since then, Patty’s been part of the group overseeing Sterling Area Services, a small nonprofit agency based in Morrisville, Vermont, for several years. For her, it’s an opportunity to give something back to the community that has come to accept her as a valued, contributing member: “I bring to the board my background; there are few people on the board in wheelchairs.”

Many self-advocates in Vermont serve on various boards and committees, including those within the system of services for people with disabilities. Some sit on the statewide Developmental Services Program Standing Committee; others on the Board of Managers of Green Mountain Self-Advocates, a statewide self-advocacy organization; and still more sit on the state Developmental Disabilities Council and boards of directors and standing committees for area designated agencies. Vermont’s disability services system has made a firm commitment to ensuring that self-advocates and family members have a place at the decision-making table. When the state went through a systemwide restructuring in the mid-1990s, participants in the change process began to recognize the importance of including people who receive services in system governance structures. As rules were written implementing Vermont’s Developmental Disabilities Act, passed in 1996, language was inserted requiring a majority of members on local agency boards of directors and standing committees be made up of people who receive services and their families. Agencies began to actively recruit self-advocates and family

members in their area to serve in these and other leadership roles. Patty describes her role on the board: “I need to teach other self-advocates, providers, directors. Because they are helping me, they have to learn from me.”

Born and raised in Vermont, Patty lived for seven years at Brandon Training School, the state’s now-closed institution for people with developmental disabilities. Since 1997, she’s had her own apartment, which she calls “Patty’s Pad.” She works part-time as a facilitator for the Vermont Self-Determination Project, and has served on several local and statewide committees and task forces. As a board member, she attends monthly meetings. Patty says that she gets along well with others on the board: “I find them very friendly, helpful, always willing to listen.” For her, it’s a way to make a contribution to the community, and an opportunity to take part in the governance of a system she relies on to support her. Patty laughs when she describes why she likes this volunteer role: “I just go, and learn, and give.”

Still, there are times, she says, that “I need help when there are things I don’t understand. Sometimes I go in early and [the Executive Director] goes over things with me.” Vermont has learned a lot about supporting people with disabilities to be real participants on governing boards. Three years ago, the Vermont Developmental Disabilities Council developed a curriculum and guide called *Boards of the Future! A Participatory Guide for Building Inclusive Board Membership*. The curriculum helps new and seasoned board members learn about board service so that it is truly participatory and empowering for all.

Since this curriculum has been in place, boards in Vermont have learned to provide accommodations to all their members that allow them to participate more fully. Through a mentorship pro-

cess, boards can bridge to becoming a stronger, more knowledgeable group. Sometimes, modifications are simple: arranging the meeting room differently or introducing everyone at the beginning of meetings or even just holding the meeting at the same place and time



every month. Usually, boards can decide for themselves what changes to make to ensure that everyone has an equal role.

For Patty, there’s a bottom line. She feels strongly that she has much to offer this and other groups with whom she works. Through her role as a board member, she has come to see herself as a leader, one in which traditional roles are redefined, and that implies an obligation for both herself and others: “I’m the teacher. I have to teach people – they have to learn from all the self-advocates. [I bring] background, experience.” Patty wants to branch out, try something new, maybe “serve on a board that helps children.” Her background and experience – along with her exuberant laughter and good humor – have made her a respected and trusted part of the community in which she lives.

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## Volunteers in the Office and the Woods: Wilderness Inquiry

by Vicki McKenna

It's about one o'clock on Friday afternoon, and the quiet of the Wilderness Inquiry (WI) office is brought to life by the sounds of laughter and loud chatter coming up the entry ramp. The group from TBI Metro Services has arrived for its weekly volunteer activity. The seven individuals with brain injuries and their two support staff are ready to work. For over five years, they have been providing an important service to Wilderness Inquiry's operation.

The day's project is laid out for them with clear instructions as to what needs to be done. One week it could be preparing informational packets for distribution to potential donors; today it is preparing 200 news releases for mailing to newspapers across the country. This is vital work for WI and the volunteers feel proud to be able to contribute to their community in this way.

It's a team effort as the workers get down to business. The assembly line is set up, several fold and pass to others to stuff. Then the sponges come out for the sealing process. The volunteers from TBI have had severe traumatic brain injuries, the results of which have left them with various disabilities and challenges. It may seem an easy task to fold some papers and stuff them into an envelope, but if your brain injury has left you with the use of only one arm, the challenge becomes one of adapting, re-learning, and changing the way you do things.

Wilderness Inquiry is nationally recognized as a leader in promoting social integration through its outdoor adventure program. The organization was founded in 1978 with the mission to provide wilderness experiences to persons of all ages, abilities and backgrounds. People with and without physical and cognitive disabilities paddle and camp side-by-side – learning to appreciate and respect the differences and abilities of each other.

During its 23 years of supporting people with disabilities in its programs, WI has developed a Universal Program Participation Model (UPPM) and organizational philosophy that purposefully integrates people with a wide range of disabling conditions as peers in each of its outdoor recreation and adventure programs. This includes people with physical, sensory, cognitive, and emotional disabilities. But in order to fully realize integration of all individuals into the community, the process must continue in the real world. The lessons learned in the woods of northern Minnesota also apply in the office buildings of Minneapolis. Every individual deserves respect and the opportunity to contribute to society. WI applies this same philosophy of social integration in its volunteer program.

Jill McKibbins, a Service Planner with TBI Metro Services, said people with brain injury volunteer for the same reasons as anyone else. "Everyone wants to feel needed, as though we count and are contributing members of a community. Volunteering is a way to give back to and be a part of something valuable, and it helps build self-esteem and confidence," says Jill. It also helps people with brain injury rebuild skills necessary for the workplace. "It's a chance to build bonds, develop teamwork, and relationship skills, to practice working and getting along with one another, so that they can then move on to paid work and be successful," she notes.

Both WI and TBI Metro Services work to educate and integrate the community by bringing people with and without disabilities together and teaching them how they can learn and benefit from one another. Among the regular volunteer opportunities at WI in which this is practiced in a manner that also supports the organization are:

*[McKenna, continued on page 27]*

### Supporting Outdoor Adventures: CH's Story

*C.H., age 35, was in an accident when he was 14 that resulted in a traumatic brain injury. He lives fairly independently in an assisted living complex and works in the community as part of a supported team of people with brain injuries. He's successful in his home and work environments, but his brain injury does play a role in his life, as it always will. C.H. sometimes feels as though he is stuck at age 14.*

*C.H. has been coming to Wilderness Inquiry with the Friday afternoon group for over a year. He likes volunteering because it gives him an opportunity to get out into the community and be productive. He can practice the skills he knows and learn new ones without paying an instructor. He also enjoys the environment at WI. The people are nice and it doesn't feel as rigid as paid work can be sometimes.*

*C.H. recently participated in a special program at WI that focused on further developing the social skills that help him to be accepted in integrated settings. He and nine other individuals with cognitive disabilities went on a five-day camping and canoeing adventure in Voyageurs National Park during which staff helped participants learn how to work cooperatively in a wilderness setting. He had a good time, in spite of the mosquitoes always finding the one place missed by the repellent.*

Contributed by C.H. and by Jill M McKibbins at TBI Metro Services.

## ***Full Inclusion in National Service: The Everyone Can Serve! Project***

*by Catherine E. Ford, Darlene W. Coggins, Vicki Hicks Turnage, and James R. Meadours*

Darlene Coggins stated her mission in life during an interview to become a member of the Georgia Personal Assistance Service Corps (GA PAS Corps/ AmeriCorps), an AmeriCorps project at the Institute on Human Development and Disability (IHDD), University of Georgia. She was asked why she wanted to be an AmeriCorps member, and she said, "Because I found my voice and I want to help others find their voices." She had literally and figuratively found hers at her first People First meeting

***The goal of the Everyone Can Serve! project is to make the full and meaningful inclusion of men and women with cognitive disabilities in national service a reality.***

some years earlier; when asked to introduce herself, she spoke her name for the first time in a very long time, having been silent because of fear and because of being told to "Be quiet" much of her life. From that significant beginning, she went on to enroll in AmeriCorps as a self-advocate member to help build the skills of self-advocacy in others with cognitive disabilities.

Although the GA PASCorps/AmeriCorps has included members with disabilities since its inception in 1994, Darlene became the first self-advocate member in the Corps when she joined in 1999. As a self-advocate, she assists others with cognitive disabilities to develop their own self-advocacy skills. The following year, 50% of the GA PASCorps/AmeriCorps was made up of

people with disabilities serving as self-advocate members. This transformation in the scope of provision of service is a natural result of the history of support of self-advocacy efforts by IHDD.

In 1997, IHDD was asked by the board of directors of People First of Georgia for assistance in the administration of the state chapter and support in the form of office space and state advisors. Answering the request, IHDD has provided support and assistance in all aspects of the organization, including assisting in the creation of local and regional chapters and in the recruitment of advisors for each chapter. Darlene Coggins, now president of People First of Georgia, says the state chapter would not exist without the support of IHDD.

This history of support of self-advocacy at IHDD has resulted in the successful funding of the Everyone Can Serve! project, a disability outreach initiative funded by the Corporation for National Service, the governing entity for national service programs across the United States. Working with Self-Advocates Becoming Empowered (SABE), the national grassroots organization representing state and local self-advocacy organizations, IHDD formulated the Everyone Can Serve! project to increase the capacity of national service programs such as AmeriCorps, VISTA, and Senior Service Corps to include and support people with cognitive disabilities as members and volunteers. The title of the project was inspired by Dr. Martin Luther King, Jr.'s quote that "Everybody can be great because everybody can serve...You don't need a college degree to serve, just a heart full of grace and a soul generated by love." The idea to collaborate with SABE was the brainchild of Dr. Jenny Manders, the Program Development Coordinator of IHDD. Armed with the self-advocate mantra "nothing about us without us," the project team

made preparations to meet with the SABE Board of Directors in 2000.

At that time SABE was nine years old. It had been established in August, 1991, when more than 800 self-advocates from the United States and Canada met in Nashville, Tennessee, for the second North American People First Conference. They set forth the mission of SABE, which is to ensure that people with disabilities are treated as equals and provided the same opportunities to make decisions and choices about their lives as people without disabilities. SABE believes that people with disabilities are empowered by speaking up for their rights and taking responsibility for their lives. In August, 2000, representatives of IHDD met with the SABE board to answer questions about the proposed partnership and how the project fit into SABE's strategic plan. Many of the SABE members had been involved with VISTA and AmeriCorps and wanted to make sure that the project would focus on people with cognitive disabilities. The board felt it was important that national service project directors know how to support people with cognitive disabilities so they can be involved in national service experiences as members or volunteers. The board discussed how self-advocacy organizations and their members have a long history of involvement with Corporation for National Service projects. Many state self-advocacy organizations have served as project sites for VISTA and AmeriCorps, including Tennessee, Oklahoma, New York, Missouri, and Georgia. These projects have focused on building self-advocacy in each state, and have resulted in some of the strongest self-advocacy organizations in the nation. The current chairperson of SABE, James Meadours, is a former VISTA volunteer and at the meeting he shared his experiences. He became a VISTA volunteer in Oklahoma after hav-



ing been involved in self-advocacy as a state and local leader. According to James, his work with VISTA provided the opportunity to continue his involvement with self-advocacy by moving into the role of a community organizer. He also said he has gained much self-confidence in his skills as a leader and that this has led to his current career as a Self-Advocacy Facilitator for the Louisiana Self-Advocacy Project.

The board decided to work with IHDD on Everyone Can Serve! because the project would help SABE work on their goals of developing self-advocacy in the states and would provide the members with new opportunities to learn to be leaders in their states and regions. The board appointed a committee to work with IHDD in writing the grant and developing a budget. As a result of this partnership, the Everyone Can Serve! project was presented to and funded by the Corporation for National Service in 2001, with SABE playing a major role in all aspects of the grant.

The goal of the Everyone Can Serve! project is to make the full and meaningful inclusion of men and women with cognitive disabilities in national service a reality. The goal will be achieved by assisting national service programs to encourage greater participation of people with disabilities in their programs and by providing information about opportunities for national service to self-advocates with cognitive disabilities.

Men and women with both physical and cognitive disabilities who are leaders in the disability rights movement and who have participated in national service programs have been involved in the development of the project from its inception, and play integral roles in the project as planners, trainers, and evaluators. Thus, the project not only provides critical information to participants, but also serves as a model for the inclusion of people with cognitive disabilities in leadership roles. The project is being piloted in Georgia in the first year and will expand to Alabama, Mississippi, and Louisiana in the second year. Major components of the project include:

- Development of a curriculum of support and inclusion for the training of national service program directors and a stand-alone resource for national service programs.
- Project team visits for programs in each state for on-site consultation.
- Development of a national service committee of the SABE board.
- Development of a national service Web page on the SABE Web site to publicize national service opportunities and provide project updates to SABE members.
- Articles in the SABE newsletter.

The project planners hope that at the end of the two-year Everyone Can Serve! project, a national model for replication will remain to foster the further inclusion of people with cognitive disabilities. To quote Darlene Coggins, "The project goal is to have an Everyone Can Serve! Network across the nation," helping self-advocates take their rightful place as full and contributing members of their communities.

National service is an excellent opportunity for people to give to their communities through service and volunteerism, and to be viewed by others as not only contributing members of the community, but as problem-solvers and leaders. As self-advocates continue to assume leadership roles in their communities and access the opportunities provided through national service, the dream of full inclusion is one step closer.

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## A Lexicon of National Service Initiatives

- **National Service:** The term used for programs and services delivered as part of the National and Community Service Act of 1990 (amended) and the Domestic Service Act of 1973. FFI visit [www.nationalservice.org](http://www.nationalservice.org) on the Web or call 202/606-5000.
- **Corporation for National Service:** Established in 1993 under the National and Community Service Act, the Corporation gives more than a million U.S. citizens opportunities to improve their communities through service. It supports service at the national, state, and local levels, overseeing three main initiatives: AmeriCorps, Learn and Serve America, and National Senior Service Corps. FFI visit [www.cns.gov](http://www.cns.gov) on the Web, or call 202/606-5000.
- **AmeriCorps:** A national service program that engages thousands of Americans, 17 and over, in community service and provides education awards and a small living allowance in exchange. Programs include AmeriCorps State and National, AmeriCorps-VISTA, and AmeriCorps-National Civilian Community Corps. FFI visit [americorps.org](http://americorps.org) on the Web or call 202/606-5000.
- **AccessAmeriCorps:** A project funded by the Corporation and begun by UCP (United Cerebral Palsy) to provide training and technical assistance on the inclusion of people with disabilities in AmeriCorps programs for state commissions on volunteerism, AmeriCorps program directors, and Corporation staff. Beginning in October 2001, the National Service Inclusion Project at the Institute for Community Inclusion (ICI), Boston, will be the new provider of training and assistance. FFI visit [http://www.ucp.org/ucp\\_generalsub.cfm/1/6619/6621/](http://www.ucp.org/ucp_generalsub.cfm/1/6619/6621/) or call Paula Sotnik, ICI, at 617/355-4788.

## ***“Our Experience is the Best Teacher”: Self-Advocacy/AmeriCorps of New York***

by Steve Holmes

For the past three years, the Self-Advocacy Association of New York State, Inc., a not-for-profit, statewide self-advocacy organization controlled by individuals with developmental disabilities, has sponsored an innovative project through AmeriCorps, a program of the National Service Corporation administered through the New York State Office of Volunteer and Community Service. The project, called Self-Advocacy/AmeriCorps, operates a speaker's bureau of persons with developmental disabilities who are self-advocates and who teach others about self-advocacy “throughout our system of supports and our communities.”

### ***Focus of SA/AmeriCorps***

The mission of SA/AmeriCorps is to help contribute to the creation of a world where all individuals with disabilities can become full and valued members of their communities. Through this project, individuals with developmental and other disabilities work under the concept that, “Our experience is the best teacher.” With this in mind, teams of SA/AmeriCorps members make presentations on a number of related topics to students with and without disabilities, teachers, people with disabilities interested in self-advocacy, staff of support service agencies, and members of the general community. The purpose of these presentations is to promote the importance of self-advocacy for people with disabilities, increase general awareness of disability-related issues, and to teach about the important gifts that people with disabilities have to offer, which can only be received through full community inclusion and participation in their own communities. A key theme of AmeriCorps is “getting things done,” which emphasizes the importance of community service for all Americans.

Each AmeriCorps project has a service that it conducts or supports and an outcome that relates to helping to build communities. SA/AmeriCorps' main contribution is that it teaches the community, through presentations and volunteer community service, that no community is complete and fully vibrant unless it includes the contributions and gifts of all its members.

### ***Organization of SA/AmeriCorps***

This project is somewhat different from the typical AmeriCorps project in several key ways: 1) most of our members are part-time; 2) SA/AmeriCorps is a statewide project; and 3) by intent, the vast majority of our members are people with disabilities. AmeriCorps in general provides funding to support members to participate in community service full-time, and members receive a living allowance stipend and an education award that can be used for college and other coursework. SA/AmeriCorps receives funding to support 24 full-time members. However, because many of our members prefer part-time service, SA/AmeriCorps has supported 55 members in each of the past three years.

SA/AmeriCorps members are divided into teams of two to four members based on interest and geographic location throughout New York. Each team and virtually each member develops an individual plan to complete personal and team activities. Most SA/AmeriCorps members participate in presentations to schools, agencies, and community organizations. Through the first three years of the project, members have made over 1,000 presentations to 25,000 people.

The themes of the presentations vary but are based on the concept that people with disabilities, through their life stories, opinions, experiences, and knowl-

edge have a lot to teach people. For instance, members present the list of “The Top 10 Things You *Shouldn't* Do When You Support Us” :

- Don't think we don't think.
- Don't change your tone of voice when you see us or we come into a room.
- Don't touch our property or move our equipment without asking.
- Never ask someone else what we want – ask us.
- Don't make decisions for us.
- Don't have meetings about us without us.
- Don't talk to us in an authoritative way or with a “sing-song” tone.
- Don't discount our abilities.
- Don't think that those of us with disabilities are all the same – we're all different, including you.
- Don't patronize us.

They also present the “Top 10 Things You *Should* Do When You Support Us”:

- Forget the records, get to know us as people.
- Listen and hear our voice; we've got lots to say.
- Treat us like you want to be treated – with respect and dignity.
- Ask us how we feel about stuff.
- Make your goal helping us accomplish ours.
- Take time to explain things if we don't understand something.
- Put yourself in our shoes – walk our walk.
- Tell us the truth.
- Believe in us, and our dreams.
- Be good to yourself – we need you to be healthy and energized.

In a short time, the project has quickly caught on in New York. For example, SA/AmeriCorps teams have become a key component of the staff orientation and training of many organizations that support people with disabilities. Using personal stories and presentations of the 10 “Dos and Don’ts”, members teach staff, including direct support staff, administrators and service coordinators, the importance of listening to the people they support and understanding who really works for whom. Our experience with these presentations mirrors the experience of self-advocacy in New York and across the country: When self-advocates have an opportunity to share their stories, their hopes and their dreams, people’s attitudes change and bridges are built to community participation. Many staff of agencies who have attended the presentation report having a completely different attitude toward their work.

### **Impact of SA/AmeriCorps**

Thus far, the overall impact of SA/AmeriCorps has been significant on many levels. People with disabilities are seen in these presentations and their volunteer work as making a major contribution to the “system” that provides support and to their community. SA/AmeriCorps members gain an increased sense of confidence and empowerment through these efforts and people grow in their leadership and personal capacity to advocate for themselves and others. In addition, members, some who were shy and nervous about speaking, have become great presenters and speakers and many have been asked to participate on boards and planning councils in their communities. Most have made great contacts in their communities and the organizations they visit. Many of the members speak of this experience as one of the best of their lives.

The Self-Advocacy Association of New York State has grown significantly as a result of this project. The number of presentations and the participation in community and system activities like

staff training has given the organization increased visibility throughout the state and has significantly increased self-advocate opportunities for participation in regional and statewide planning councils and boards. We’ve learned a lot of lessons from this project and there have been many challenges, not the least of which is finding ways to support and accommodate people to complete their membership activities. Members, for the most part, do not travel to the same work place every day but to presentations at various community locations. Transportation, not surprisingly, has been a monumental challenge for all and especially for our many members who require accessible vehicles.

We’ve also been reminded of what we already knew, that people with disabilities are ready for the opportunities for community service and anxious to contribute and make a difference for themselves and others. The biggest obstacles are the challenges of putting together the right supports to meet their individual needs. In most ways, these are the same challenges that many people with disabilities face in trying to find meaningful work. In fact, that is one of the big challenges for members when they are finished with their terms of service – finding a good job or volunteer situation that provides a comparable level of personal satisfaction and opportunity for growth as an AmeriCorps membership.

We believe that the members of SA/AmeriCorps teach a great lesson about the importance of contribution and service to their communities. But more importantly, members teach that we should never underestimate what people can accomplish with support. The gifts and wisdom displayed by the members of SA/AmeriCorps are great example of what people can do with an opportunity.

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### **A Team Member: Kim's Story**

*Are you a member of a team? I'm involved with the Self-Advocacy Association of New York State, which has a grant from a national service organization, AmeriCorps, and I live by its ideals. AmeriCorps is the best thing that has happened to me. This great experience has given me the opportunity to teach other people about individuals with disabilities. Because I have cerebral palsy, it is extremely important to me that people see me first, my abilities, not just my disability. I have had some bad encounters because of my wheelchair. With AmeriCorps, I am able to turn those bad memories into valuable lessons for other people! People respect me and my teammates when we give presentations. So many businesses are afraid to hire the people with disabilities. But AmeriCorps looks at our abilities, not our disabilities. While we are in AmeriCorps, we also receive training that helps us with our personal growth and prepare us for future endeavors.*

*Being a member of AmeriCorps means the world to me. The coordinator, team leaders, and the other members make me feel very welcome and comfortable. My AmeriCorps team is my second family. With them, I am doing something that is very important to me, with people I really enjoy!*

Contributed by Kimberly Ann Hennen, Spencerport, New York.



## Resources

*The following resources may be of use to readers of this Impact on volunteerism. For information on obtaining publications, please contact the distributors listed. Inclusion on this list doesn't necessarily imply endorsement.*

### Publications

- **Utilizing All Your Resources: Individuals With and Without Disabilities Volunteering Together** (1996). This manual discusses strategies for enabling individuals with and without disabilities to volunteer together in their communities for fun and civic service. Topics covered include recruiting, training, liability for, challenges of, and coordinating volunteers. Available from Publications Office, Institute for Community Inclusion, Children's Hospital, Boston • 617/355-6506 (voice), 617/355-6956 (TTY). Order #RES1.
- **Boards of the Future!: A Participatory Guide for Building Inclusive Board Membership** (1999). By Burdett, C., Hartnett, J., Lacroix, D., and Richards, J. These manuals were created to accompany (and assist facilitators in leading) workshops on inclusion of persons with disabilities on organizational boards. *Boards of the Future* is a learning tool for all types of decision-making groups, and is meant to develop a collaborative leadership environment within the workshop and on boards. Available from Vermont Developmental Disabilities Council, Waterbury • 802/241-2612 (voice/TTY), 888/317-2006 (voice/TTY).
- **Not Another Board Meeting! Guides to Building Inclusive Decision-Making Groups** (1994). By Gobel, S. & Flynn, J. A very useful tool for self-advocates, support persons, and board members seeking to include persons with disabilities in decision-making groups such as organizational boards. It includes separate materials suitable for making

overhead transparencies for training for each group separately or all together. Very accessible format, with people-first language. Available from the Oregon Developmental Disabilities Council, Attn. Jill Flynn, Salem • 503/945-9941.

- **People First of Washington Officer Handbook.** This handbook can be used to teach people with developmental disabilities about the basics of board membership. Includes explanations of the typical officer roles on a board, simplified Robert's Rules, and other essential information. Available from People First of Washington, Clarkson • 800/758-1123.
- **Leadership Plus** (1995). By Hoffman, M. Three very helpful manuals to support leadership by persons with disabilities. The participant manual assists people with developmental disabilities to develop and initiate their leadership, self-advocacy, and self-determination skills (including much on board participation). The facilitator's manual assists facilitators to take people with disabilities through the Participant Manual. "I Make a Motion Too" is a brochure-like guide that assists in the understanding and inclusion of the roles of people with disabilities on public boards and committees. Materials are suitable for making into overhead transparencies, and include activities and role playing suggestions. Available from Tulsa ARC, Tulsa, Oklahoma • 918/582-8272.

### Web Sites/Listservs

- **The Virtual Volunteering Project** (<http://www.serviceleader.org/vv/>). The purpose of the project, which is based at the University of Texas, is to encourage and assist in the development and success of volunteer activities that can be completed, in whole or part, over the

Internet. It recognizes that many people desire volunteer activities they can complete from their homes, and that use of the Internet opens up additional volunteer options. Included in the site is information on the benefits of online volunteering for persons with disabilities, strategies for recruiting and involving people with disabilities in online volunteering programs, and personal stories of individuals with disabilities who have been virtual volunteers.

- **Internet Nonprofit Center Web Site** (<http://www.nonprofits.org>). This Web site includes a listing of resources titled "Organizations That Promote Volunteering by Persons with Disabilities." The list includes links to the Web sites of the organizations and descriptions of what they offer.
- **Service and Inclusion: A Multimedia Resource for Inclusive Community Service** (<http://www.serviceandinclusion.org>). This Web site documents the active participation of people with disabilities in community service through national service programs including AmeriCorps, National Senior Corps, and Learn and Serve America. The content is meant to encourage and support the participation of persons with disabilities in national service programs, while offering resources to organizations seeking to increase the involvement of persons with disabilities in community service. Included in the site are excerpts from interviews with individuals with disabilities who have participated in national service programs; they talk about what they have contributed and gained, and offer advice to programs seeking to successfully include people with disabilities. Also included are links to disability resources and national service programs, as well as a glossary of disability and national service terms.

- **National Service-Learning Clearinghouse Web site** (<http://www.servicelearning.org>). This Web site has a section on service learning and individuals with disabilities that lists publications and organizations offering information on service learning and youth with disabilities.
- **Texas Commission on Volunteerism and Community Service Web Site** (<http://www.txserve.org/programs/disability>). The Web site has materials designed for AmeriCorps programs seeking to include members with disabilities, and of use to other organizations involved in community service and volunteerism. Among the materials are fact sheets on "Including Members with Disabilities in Your Service Program: Recommendations for Developing a Recruiting and Application Process That is Accessible to Persons with All Types of Disabilities," "Interviewing Persons With Disabilities," "Practical Suggestions for Recruiting Members with Disabilities," and "Identifying Essential Job Functions." The site also includes links to other resources the support fostering diversity in volunteer and service programs.
- **Disabilitylist Listserv**. This listserv has been created to facilitate communication among national service programs, providing a forum for programs to share information and resources and to discuss issues related to the sustainable development of national service experiences for persons with disabilities. The list is open to anyone interested in the topic area. To subscribe go to <http://lyris.etr.org/scripts/lyris.pl?enter=disabilitylist>.
- **VolunteerMatch.org**. This Web site is dedicated to helping everyone find a great place to volunteer. Volunteers enter their ZIP code on the Web site to find volunteer opportunities posted by nonprofit and tax-exempt organizations in their area. Volunteer-Match Corporate is a custom-

ized, co-branded version of Volunteer-Match licensed to corporations to make it easier for employees to volunteer. Information about both is found on the Web site.

- **National Service Resource Center Web site** ([www.etr.org/nsrc](http://www.etr.org/nsrc)). The NSRC operates a resource library with a wide range of resources for programs funded by the Corporation for National Service. The library catalog can be accessed online. Among the items available for borrowing from the library are "Activity Guide to Inclusion of People with Disabilities" by Helen Lowery (#C1203) and "Youth Volunteer Corps: Training Manual for Working with Youth Volunteers Who Have Disabilities" by White, Froehlich, and Knight (#C1202).
- **International Year of Volunteers Web site** ([www.iyv2001us.org](http://www.iyv2001us.org)). The United Nations General Assembly proclaimed 2001 as the International Year of Volunteers. It's a year-long opportunity for increased recognition and promotion of volunteering worldwide. On the Web site is an array of materials about volunteerism in general, and an opportunity to register as a partner in the effort as well as find out what other partners are doing.
- **Questions and Answers From the Access: Opening the Doors Conference** ([www.nationalservice.org/resources/cross/index.html](http://www.nationalservice.org/resources/cross/index.html)). Responses to questions concerning legal responsibilities, reasonable accommodations, program accessibility, disability funds, member compensation, and recruitment as they relate to including people with disabilities in national service.

## Addressing Possible Loss of Disability Benefits for Service Participants

*One factor that has kept people with disabilities out of the workforce is the loss of disability benefits including Medicaid and Medicare. While service is different from employment, participation in some national service programs may threaten eligibility for government assistance programs in the same way that a job would. Thus an individual on federal assistance is likely to have real or perceived economic barriers between them and service. Congress has recently passed legislation to address the loss of benefits, but these work incentive programs are somewhat complicated and many people don't know about them.*

*Service programs that are recruiting people with disabilities will benefit from some familiarity with these issues and the work incentives options that are now available. It is recommended that programs let all applicants know that national service may have an impact on benefits so the information reaches all recipients, whether or not they self-disclose; make sure the individual understands the potential economic impact of service before they join a program. Each individual with a disability will be impacted differently, so it is important that they get information for their particular situation from their local Social Security Administration office and other agencies that are familiar with the Work Incentives Program.*

*For up-to-date information on the relationship between disability benefits and national service participation, contact the Social Security Administration. 800/772-1213 (voice), 800/325-0778 (TTY), or [www.ssa.gov](http://www.ssa.gov).*

Excerpted with permission from *Service & Inclusion: A Multimedia Resource for Inclusive Community Service* ([www.serviceandinclusion.org](http://www.serviceandinclusion.org)), a Web site developed by Emily E. Miller through her fellowship with the Corporation for National Service.

*Tischler, continued from page 1*

I am a happy-go-lucky guy and I love working with children and helping them learn new things. I love to read, write stories, sing, and I am a very good artist. Mostly, I like to make people feel good. Everyone has sad or bad things that happen to them, and if I can make them feel better, then I feel better. Everything I write and do is from my heart and out of my chest. I can tell when people are hurt or sad about things, and so I like to make them laugh or feel good about

***Having Down syndrome sometimes bugs me, but mostly I know I have a lot to give back, and when the kids are curious about it, I just tell them about it and then they just go on reading or playing.***

themselves. Sometimes I get frustrated or sad, but I just write a story or draw about my feelings and then go out and help someone else. That makes me feel better.

I worked unpaid at Monroe Community School as part of a work-training program while I was still in high school. I used to go to Monroe when I was in middle school. It is close to my home and I can walk there. Some of my duties were to help Bob, the custodian. He found lots of things that he needed help with and I got to be around all the kids, which I love. Eventually I was hired as a full-time teaching assistant, but still wanted to help Bob. I like being busy and around people, so Bob said that I could help him in the lunchroom during lunch. I mop, clean windows, carry out trash, and do whatever needs to be done.

When the school budget cuts came I lost my job as a TA along with a lot of other people. The Wilder Foundation has a program at Monroe called Achievement Plus. I used to volunteer with their program in the library, putting books back on the shelves, fixing them, and helping the students find books. So, they hired me for four hours a day and I got a job with food service two hours a day, so I was able to stay at Monroe. I start at 7:30 a.m. with Achievement Plus helping kindergartners and first graders with math and reading. From 9:00-11:00 I work in the food service. After lunch I help Bob in the lunch room; this is volunteer. After more time with Achievement Plus I go to the library and help organize and stamp books. My day usually ends at 3:30. If there is a carnival or other school event I volunteer to come back at night to help where I am needed, and if there are conferences or special meetings I stay late to help get everything ready. In the fall, when my summer job is over I go over to Monroe and help the custodian get the school ready for when it opens. I like to help and it's fun for me to work with the guys, who are my friends.

I love working with the kids. It's a good experience because I was their age once and it was my dream come true when I started growing up. My mom was always there for me and did a good job of raising me. Jack (my mom's husband) did half of my life. He's funny and fun to be with.

I also volunteer at church with Vacation Bible School and sometimes with Sunday school. I used to go to the Bible school and then I got too old. I didn't want to give that up so I asked if I could come and work with the kids. I read Bible stories to them and help them make pictures about the stories so they can learn about Jesus.

In the summer, I get bored when my teacher aid job is on break. There is a day care center by my house and sometimes I volunteer with them. I read to the little kids and play in the playground. Sometimes I take the little ones for a walk in the stroller.

Those are the things I do that are at places in the community, but I also try to look for things that other people need just walking around. Sometimes kids at school are too late for the crossing patrols so I help them get back home. I know my neighbors and if they need help I like to pitch in. When I am out with my community support person or on respite, I like to help in the kitchen or with any of the work that needs to get done. It is just more fun to be with people with whatever they are doing instead of just being by myself. Plus, I make people laugh and that is fun.

Having Down syndrome sometimes bugs me, but mostly I know I have a lot to give back, and when the kids are curious about it, I just tell them about it and then they just go on reading or playing. I think they like my smile and that I am patient; I don't get mad. They probably like my drawings, too, because I draw lots of cartoon people and make their faces really expressive. I can draw happy, scared, mad, frightened, and surprised faces. That makes them laugh and know that I care about their feelings.

I know that not everyone gets a chance to do all the volunteer stuff that I do. I am the fourth generation of my family living in the West Seventh Community and people know my mom and they knew my grandparents and great grandmother. There are lots of good people who live here and when my mom talks to them about me volunteering they know us and they have been really open and welcoming to me. I don't want to leave my neighborhood or my old school because people care about me and my family. That makes me feel good about giving back, makes me feel like I am part of my community and I don't want to let them down.

*Vernon Tischler lives, works, and volunteers in St. Paul, Minnesota. Kris Schoeller is a training coordinator and transition specialist with projects at the Institute on Community Integration, University of Minnesota. She may be reached at 612/624-2376 or by e-mail at schoe043@tc.umn.edu.*



*Walker, continued from page 15*

the choir, Danielle also got involved with a self-advocacy group. When the self-advocacy group was notified of a class that would be given for self-advocates about joining boards of directors of agencies and organizations, Danielle decided to take this class. After taking the class, she decided she wanted to join the choir board. Danielle feels that being on the board has been a good way for her to get more involved, help out the choir, and get to know more people. At first, at the board meetings, it was difficult for her to hear what was going on, as a number of people were talking at the same time. Since she raised the issue, board members are now more careful about speaking one at a time. Also, in addition to their usual typed minutes of meetings, the board records minutes on tape for Danielle.

***Danielle decided she wanted to join the choir board. Being on the board has been a way for her to get more involved, help out the choir, and get to know people.***

Overall, Danielle says, "Choir is great. I've met lots of new people and made good friends. Being on the board, I feel like I'm helping the choir out." She hopes to continue this involvement for quite some time.

*Pam Walker is Research Associate with the Center on Human Policy, Syracuse University, Syracuse, New York. She may be reached at 315/443-4290 or by e-mail at pmwalker@mailbox.syr.edu. Danielle lives, work, and volunteers in Syracuse.*

*McKenna, continued from page 19*

- Volunteer night on the first Wednesday of each month. Two WI staff coordinate the work done by individuals of all physical and cognitive abilities. Several of the regular volunteers have developmental and learning disabilities. Following the same philosophy that WI employs in its outdoor adventures, every job is subdivided into tasks that allow everyone to participate. No one is left sitting off to the side, just watching. In addition to the work, the evening is also a great opportunity for socializing while eating the pizza provided by WI.
- Free outdoor skills workshops conducted by WI throughout the year, which could not take place without volunteers of all abilities. They perform a variety of tasks from strapping snowshoes on participants at St. Paul's Winter Carnival to helping people find the right size paddle at a Minneapolis canoe event. One young man with a learning disability has been so valuable at these workshops that he has been hired as a part-time trail staff for the summer.
- Sunday nights during the summer months, volunteers assist with pack-ins – sorting and cleaning equipment used on wilderness trips.

Wilderness Inquiry currently serves over 40,000 individuals of all ages, backgrounds, and abilities annually. With fewer than 20 full-time staff, this would be impossible without volunteers and a deep commitment to the mission of the organization. Social integration is just as important in the office as it is in the woods.

*Vicki McKenna is Director of Administration with Wilderness Inquiry, Minneapolis, Minnesota. She may be reached at 612/676-9427 or by e-mail at vickimckenna@wildernessinquiry.org.*

## ***The National Service Inclusion Project***

*The Institute for Community Inclusion, a University Center of Excellence at the University of Massachusetts in Boston, is partnering with the American Association of University Affiliated Programs and the Corporation for National Service to operate the National Service Inclusion Project. The project, which began this fall, will implement a comprehensive program of training, technical assistance, and dissemination designed to increase the participation of individuals with disabilities in national service programs, including AmeriCorps, Learn and Serve America, and National Senior Service Corps. To assist these programs in carrying out their commitment to inclusion, the project will develop and implement the following:*

- *Regional, state, and program-specific training and technical assistance.*
- *Ongoing needs and preference surveys to ensure applicable and meaningful training and technical assistance.*
- *A "one stop" interactive Web site.*
- *Strategies to develop state and local partnerships between Corporation for National Service grantees and the disability community, particularly the University Centers of Excellence.*
- *Information dissemination focusing on the opportunities for individuals with disabilities in national service.*
- *A national conference on inclusion in national service.*

*For more information on the National Service Inclusion Project, contact Paula Sotnik, Project Director at 617/355-4788 (v), 617/355-6956 (TTY) or at paula.sotnik@tch.harvard.edu.*

## *In This Issue...*

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- **Improving Volunteer Options for Persons with Developmental Disabilities**
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- **Disability Agencies and Cultural Communities: Working Together to Support Volunteers**
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## **Impact**

*Feature Issue on Volunteerism by Persons with Developmental Disabilities*

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