What is the self-advocacy movement and why is it important?

Self-advocacy is a civil rights movement that comes out of the tradition of the African American civil rights and women’s movements. We’re a little bit different, because while we do talk about civil rights and protection from discrimination our focus is more on inclusion, community education and self-transformation. The most important element of self-advocacy is self-transformation. A lot of our advocates have come from sheltered lives where parents or professionals did all the decision making for them. They needed to change from being passive individuals and to be leaders of their own life. They needed to learn responsibility, how to make decisions, and general character development.

Why did San Diego People First choose to offer a leadership symposium for advocates with developmental disabilities? What did it take to organize such a big event?

It was an epiphany, a real mountaintop experience for us. A big part of People First is leadership development and we like to see San Diego People First as the hub of self advocacy in San Diego. We wanted to build up the local self-advocacy groups and a leadership symposium sounded like a great way of doing that.

We had a ton of planning meetings. We had to find curriculum materials and a meeting site. The first site we located turned out not to be as accessible as we would like, so we had to hunt down another site. There were a number of considerations like pricing, room size and if the site was on a transit line. To recruit, we used our list of San Diego self-advocacy groups, and sent fliers to each group’s facilitator. Doing telephone follow-up was crucial, as people get so much paper on their desks that a flier alone won’t do that much.

You used a train the trainer the model. How did you develop this training curriculum?

Developing the curriculum took up most of our planning. Over the years, we had pulled some from existing resources like ACT, the Riot, and other sources from the internet. Some were from People First of California and some came from the Department of Developmental Services consumer advisory committee. We used a wide variety of sources. We didn’t want to reinvent the wheel. Now that we have curriculum resources in place, we can do more training with less preparation.

What kind of training and experiences were offered at the symposium?

We came up with activities that the attendees could take back to the group and that the groups could participate in. They dealt with leadership,
goal setting, Robert’s rules, and community service. Volunteer San Diego, our local volunteer center, did a presentation for attendees, which was followed by a roundtable discussion. That was very good. We encouraged their participation in community service by keying in on existing projects the Teddy Bear Dance and Rachel’s Women Shelter.

You found it was important to train facilitators, as well as advocates. What are facilitators and what role did you hope they would play in helping advocacy groups get involved in service?

A facilitator is a staff or support person for a self-advocacy group. They provide guidance to the group, but the group is led by self-advocates. The facilitator can help clarify values, prioritize, encourage good organizations, bring resources into the group, and act as a liaison to other organizations.

We found that we needed to have facilitators that were well educated in the content of the trainings. We needed to make sure their schedules and attitudes were in sync with ours, because our consumers have limited communication skills and some have limited executive cognitive skills -- that’s why a facilitator is so important.

Your hope was that advocates who attended this symposium would take the information back to their advocacy groups and get them involved in community service. Did this happen? What kinds of service did groups engage in?

The idea was to have people do activities in their local group and bring them in to show during regional meetings. For instance, we had started the Teddy Bear Dance the year before and this helped expand it. The idea of the Teddy Bear Dance was that we’d organize a dance and the price of admission would be a teddy bear. All donated Teddy Bears went to Children’s Hospital. So, local groups worked, on their own, to collect teddy bears and decorate them, which they then brought to the party. The self-advocates from the St. Madeline Sophie’s group made trees for the Holiday Forest which was the theme for the Teddy Bear Dance. Lots of people contributed in different ways. What’s important is that everyone felt good about the experience.

Rachel’s Shelter is another group that we had a relationship with. They’re a place where women can get back on their feet. Groups made gift baskets full of toiletries and donated them to the shelter. Rachel’s Project has turned out well. In the last year, we’ve developed a partnership with a high school. They donate items to us that we distribute to the baskets. The amount of gift baskets we produce has increased each year. As a result of our success with Rachel’s Women Shelter, we’ve recently started giving donated baskets to a safe house for women who have fled their homes.

As a result of the leadership symposium, San Diego People First developed a community service workgroup which meets every other month. Are there other ways in which the symposium strengthened your organization, as a whole?

What was once a mountaintop experience has now become the floor of what we do. We felt extremely stretched to put on the first leadership symposium. We hadn’t done anything like that and now we do it annually and it’s routine. We do one day symposiums each quarter now. And, we’ve embarked on other programming. One program that I’m excited about is a self-advocacy group for teens. We’re starting it at one high school and going from there. Being involved is a challenge for any teenager,
A particular for people with developmental disabilities who may have had limited experience making decisions and being responsible.

Also, the leadership symposium helped us developed better ties to local self-advocacy groups and that has been important. This better network helped other things evolve, like our annual speech contest, which is sponsored by Toastmasters from the ARC of East County.

It’s been two years since you started this initiative, what successes have you seen emerge? Have you witnessed long-term changes in the lives of advocates or in the responsiveness of the community?

Among self-advocates I see greater confidence, a better sense of mission, better problem solving skills, more poise, especially among officers. At least for me, I have more confidence. I’m more self-assured and more content with things.

We’re still working on inclusion in the community. We made a video about self-advocacy and People First and we are trying to get that out into the community, into classrooms and into the hands of service groups, like the Lions and Kiwanis club. We haven’t made the progress I’d have hoped in distributing those DVD’s. I think as members increase in their problem solving skills they will get out there.

Anything else you want to tell readers?

We focus a lot on dreams. We teach people to sift through values, wants and needs and then come up with action plans to reach those dreams. But I’ve reached a point where I’ve realized that dreams aren’t something you reach for, but something we live out. For example, I had a dream to buy a house, so I bought house. I had a dream of getting a full-time career, so I got that, but that in and of itself didn’t make me happy. What made me happy was when I realized that I had been living out my dreams all along and expressing them daily. Each moment I live is my dream to be cherished and celebrated.

To learn more about San Diego People First and their leadership symposiums, contact Paul Mansell at paulmansell@sbcglobal.net or San Diego Regional Center 4355 Ruffin Rd, Ste. 114, San Diego, CA 92123. Also visit the San Diego People First website to read more about their leadership series at www.sandiegopeoplefirst.com

To learn more about how to include self-advocates with developmental disabilities in community service, see the People First Community Service Inclusion Workbook http://www.peoplefirstca.org/CommunityInclusion.htm

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