

Developmentally Dis(En)abled:  
Efforts to Integrate the Developmentally Disabled into their Communities  
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**Introduction**

In 2008, I completed my social work senior practicum with the St. Louis chapter of The Arc. The Arc is the largest community-based organization in the country supporting people with intellectual and developmental disabilities. It has more than 850 state and local chapters across the nation, and each one shares the same core values. Full community participation is the Arc value I believe is essential in bringing about social justice for the developmentally disabled. I chose The Arc because its agency “works toward ensuring that all people have the fundamental moral, civil, and constitutional rights and opportunities to live, learn, work, play, and worship in communities of their choosing” (“About us,” 2008).

My task as a practicum student at the St. Louis Arc (SLARC) was to explore many of the services the agency provides, whereby I could learn about the issues facing developmentally disabled individuals. As I gained a greater understanding of the issues, I plugged in to different aspects of the agency, using my strengths and interests to address these issues. I devised six strategies by which I could fulfill needs for, advocate for, and empower the population SLARC supports. These strategies included: 1) volunteering at a Community Integration (CI) Center, so as to learn about the challenges the developmentally disabled face; 2) planning a field trip for a CI Center to an organic farm; 3) participating in a Person-Centered-Planning meeting (PCP); 4) helping to educate the developmentally disabled about the electoral process and register them to vote; 5) lobbying at the state capital for the rights of the developmentally disabled; and 6) participating in planning and executing SLARC Rest and Relaxation (R&R) weekend camps.

## **Strategy 1: Volunteering at a Community Integration Center**

The first line of The Arc's mission statement asserts that its main goal is to do everything in the organization's power to ensure "the rights and full participation of all children and adults with intellectual and developmental disabilities" ("About us," 2008). In volunteering at a CI, I learned that this key word, "participation," expresses unlimited inclusion into all that society has to offer. Unfortunately, many Americans are denied the freedoms and liberties our Constitution guarantees. Congress passed the Americans with Disabilities Act in 1990 because work areas, restaurants, libraries, medical-care facilities, housing units, and other public facilities or privately owned businesses lacked accessibility for people with physical disabilities. Restricting the disabled from entering or working in these facilities limited their rights. Today, unaccommodating structures deter those with developmental disabilities from accessing goods and services. Unlike most Americans, the developmentally disabled have few school, job, and social opportunities because their communities lack necessary accommodations. Understandably, few employers are willing to hire someone with a developmental disorder, because it is easier to train someone without one.

Obviously, many jobs are not fit for people with developmental disabilities, such as those which require critical thinking and complex math and reading skills, but excluding the developmentally disabled from all environments involving higher-level thinking can have negative effects. For example, most people with developmental disabilities are denied access to mainstream classrooms and are sent to specialized schools. While many benefits come from special education, special schools prohibit the developmentally disabled from interacting with "average" children their age. This creates two problematic situations: 1) the developmentally disabled fail to learn societal norms and socially acceptable behaviors; and 2) segregated schools

create a divide between mainstreamed children and the developmentally disabled. Many developmentally disabled people do not develop acceptable communication skills, such as how to greet others appropriately, ask for assistance, and perform other everyday interactions. For example, one man at St. Louis's North County CI Center hugs everyone, even strangers, upon greeting them. In America, people do not hug when first meeting, because an embrace only is considered acceptable for intimate relationships.

Secondly, children in mainstream schools lack interaction with the developmentally disabled, and, therefore, feel awkward around or afraid of them. This awkwardness translates into the society at large. For instance, when staff members from CI centers take program participants out to restaurants, waiters often ignore the person with the disability when collecting food orders. Servers speak only to staff members and not to the person with the disability, asking, "What will *he* have for lunch today?" Nearly all of the participants of the CI programs can communicate what they want in some form, so when they are ignored they not only feel hurt, they also become more reliant upon their staff members.

## **Strategy 2: Organic Farm Excursion**

I chose to volunteer for the SLARC CI program so that I could learn how it actually integrates the developmentally disabled into the community. I assisted in the CI program for more than three months and developed my own strategy for incorporating the participants into the community. I collaborated with a local organic farmer to plan a field trip to his farm in late May 2008. We chose a number of activities to help CI participants learn about farm work, such as planting, harvesting, cultivating, weeding, and various other jobs. Few CI participants had any concept of what a farm is, and fewer, if any, had visited a farm. As a result, when I asked CI

participants where their food comes from, they did not know what I meant. A common belief was that their food comes from a package in the store or from a restaurant. On this field trip, participants ate what they harvested to discover for themselves the connection between where their food is produced and how it becomes part of their meals.

Ignorance of food production is highly prevalent in the city and contributes to poor health. The inability to distinguish between whole foods and processed foods compels the developmentally disabled and their families to choose cheaper, unhealthy goods. This is true not just of the developmentally disabled, but also of all of the urban poor: low income and poor health go hand-in-hand, especially in inner cities. This correlation also is linked to the inaccessibility of fresh, nutritious foods in cities, particularly in poorer areas.

When one compares the accessibility of healthy, fresh food sources among cities, St. Louis not only stands out as lacking, but also has poorer health than most of Missouri's urban areas, implying a correlation between the two (St. Louis Department of Health). St. Louis City residents have a high risk of developing heart disease, diabetes, obesity, and other diet-related illnesses. Experts advise consuming at least five fruits and vegetables daily (Jackson, C., Lawton, R., Knapp., Raynor, D. K., Conner, M.; Lowe, C., Closs, S. J., 2005), and that is just not happening among low-income individuals and families in St. Louis. Studies do show, however, that low-income individuals and families will tend to consume greater amounts of fruits and vegetables when these products become more available. One study asserts that "easy access to supermarket shopping" increased fruit consumption by 84 grams per day in 95 percent of 963 Food Stamp Program participants; the inverse effect also was true, for when access decreased, fruit consumption decreased (Rose, Richards, 2004). The aim of the farm field trip was to provide CI participants with incentive to locate nutritious foods available locally.

Not only does the exposure to fresh fruits and vegetables lead to increased consumption (which thereby improves one's health), exercise keeps one fit. Health experts agree that eating nutritiously cannot stand alone if one is to remain healthy. A good diet also must be accompanied by physical activity. Another aim of the farm field trip, then, was to create an opportunity for physical outdoor activity. The plan was to make this a positive experience for the CI participants so that they would be inclined to pursue more exercise. To add to the enjoyment of the field trip, CI participants were able to interact with friendly animals—goats, chickens, cats, and dogs—which they fed and petted.

### **Strategies 3 & 4: Person-Centered Planning Meeting and Voter Registration**

The Arc takes a firm stand on the quality of life issue for the developmentally disabled, stating that it is essential that they “choose and receive the services and supports that will help them live meaningful lives” (“About Us,” 2008). The CI program includes every participant in the decision-making process regarding the services that the agency provides them by conducting Person-Centered Planning (PCP) Meetings. These meetings are designed to assist program participants in developing community-participation goals and means of reaching these goals. This is an empowerment strategy used to ensure that people with developmental disabilities make their own decisions, thus giving them the chance to experience and involve themselves in their communities.

Because each person has their PCP meeting once a year, and none of these meetings coincided with my volunteer schedule, I was not able to attend one. I did read the files of those participants I assisted, however, and these files allowed me to better support them in their quest for the goals *they* helped choose. For example, a staff member and I took Don, a participant in

the Metro CI Center, to Forest Park to walk around. Don and his PCP team decided upon an exercise goal of twenty minutes twice a week. Don does not like to exercise, nor does he have the money to join a gym. However, he likes visiting the park, and I was able to help him reach his goal by bringing him to the park and encouraging him during our walks.

Another empowerment strategy is registering CI participants to vote and educating them on the voting process, issues, and candidates. I worked with SLARC's Social Justice Committee to conduct voting classes. These classes were geared toward those with developmental disabilities who were their own guardians and were at least 18 years old. The developmentally disabled are capable citizens and deserve the same rights and freedoms of any American. Hence, the SJC uses the same philosophy as that which governs the PCP meetings, in which the person with the disability is included in drafting the policies and procedures affecting them. The SJC informs the participants of the issues and candidates in upcoming elections, trying to remain unbiased and refrain from interfering with voter choice. It has happened before that a participant has voted for candidates who oppose legislation for the developmentally disabled, and the staff supported his or her decision.

### **Strategy 5: Lobby Day**

I attended the Saint Louis University School of Social Work's Lobby Day on April 1, 2008, with the intention of advocating for legislation affecting the developmentally disabled in St. Louis and the State of Missouri. I met with State Senator Wes Shoemeyer about Senate Bill 1166, which would have provided funding for cost-of-living increases to contracted community providers for the Missouri Department of Mental Health. Contracted community providers, or Direct Support Professionals (DSPs), include personal care assistants, home care aids, and staff

in community residential programs. They assist millions of people nationwide with medications, preparing and eating meals, dressing, mobility, and handling daily affairs. DSP positions are characterized by low pay and poor benefits, which contribute to the shortage of DSPs in the United States, including Missouri (The Arc, AAIDD, AUCD, UCD & NACDD, 2008). The following are statistics on DSPs:

- In Missouri, state employed DSPs' hourly wages averaged \$7.23 in 2002 and non-state DSPs' averaged \$8.13 (Polister B., Lakin K. C., & Prouty R., 2003).
- Staff turnover among non-state community service agencies is consistently found to range from 50-75 percent per year or more, and about 20-25 percent per year in state-operated services (Polister B., Lakin K. C., & Prouty R., 2003).
- Average state DSP wages in 44 states in 2000 were only 74 percent of the average wage in these states (Polister B., Lakin K. C., & Prouty R., 2003).
- On average non-state DSPs earned only 55 percent of the average state wage in 2000 (Polister B., Lakin K. C., & Prouty R., 2003).

Many problems arise out of the high turnover rates and shortages of DSPs. For one thing, the shortage of DSPs means that agencies are forced to hire under-credentialed employees, often resulting in poor service quality. Secondly, the high turnover rate means less consistency of services, since staff members continually come and go, leaving service recipients to new, inexperienced DSPs.

### **Strategy 6: Rest and Relaxation (R&R)Camp**

The R&R program “provides opportunities for increasing independence, forming social roles, building relationships, and learning self-reliance” (“About Us,” 2008). I helped to facilitate the development of these skills by working one-on-one and in groups with campers through various activities, including arts and crafts, group games, sports, cooking, hiking, fishing, singing, music and socializing. The skills on which we worked helped participants become part of their communities as they learned to build community at camp.

Also, since participants come from urban and suburban areas around St. Louis, few of them have the opportunity to experience nature and the outdoors. In building on the organic-farm field trip, this R&R allowed campers to meet exotic animals such as emus, porcupines, ponies, birds, snakes, and many more. Mikey, the boy I supported at camp in March 2008, perked up, laughing and smiling when we showed him a turtle. The rustic atmosphere and activities gave the campers a great experience, for they stayed in cabins, walked trails, and sang and danced around a campfire for three days.

For the families of the campers, the R&R camp was a great respite. Parents, temporarily freed from caregiver roles, enjoyed having a weekend to accomplish tasks they otherwise could not complete because of having to care for their children, or simply relaxed and had some uninterrupted time to themselves. For the campers, R&R meant a step closer to independence as they experienced being away from home. Each weekend that campers experience at R&R helps them to feel more at ease in being out in their communities and on their own without their guardians



## **Conclusion**

Even though the United States has some of the best protections for individuals with developmental disabilities, there is still much upon which to improve. This is true, too, for St. Louis, it hardly an exception to patterns extant nationwide. The developmentally disabled often are overlooked here and elsewhere because their form of self-expression frequently differs from societal norms; thus, their voices are heard less often. By engaging them at CI centers and participating in R&R weekends, I was better able to understand the issues facing the developmentally disabled community. From there, I used my connection with an organic farmer to create a strategy for community integration. Also, I had the chance to advocate at the state level for better services, and I empowered the developmentally disabled to advocate for themselves by voting. Finally, I saw how I could best support all of the people with whom I was paired, learning how they developed their own goals. I hope that my work may provide inspiration for others who might seek to serve the developmentally disabled.

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