

Americans With Disabilities Seek Access, Resources

A Grassroots Advocate's Perspective

By Barbara Toomer

No matter how many laws are passed to ensure the civil rights of people with disabilities, no matter how insistent people with disabilities are that disability is not the end of the world, there persists a perception among too many Americans that people with disabilities need pity more than they need equality, that their lives are a shambles and are unworthy.

So what do worthiness and disability rights have to do with funding? Everything. Mainstream disability organizations—those seeking cures or providing services for people with disabilities—are showered with money, while those working for the rights of people with disabilities are viewed as mavericks and agitators. As “Jerry’s Kids” age, they get less money from local MS societies, even though they are still living with disabilities. Funders sometimes are under the illusion that the government provides money for people with disabilities, but mostly it is agencies that deal with medical and health-related issues that tend to get funded. Very little money goes to agencies that work to empower people with disabilities.

Colorado advocates report that many foundations do not fund advocacy groups because these groups are seen as “destroying the system,” when in reality, they are committed to advancing the civil rights of people with disabilities and to making the system fair and friendly to everyone.

For example, the Americans with Disabilities Act was passed with help from all sectors of the

disability community—but ADAPT, an organization advancing civil rights for people with disabilities, deserves much credit for the legislation’s transportation provisions. In the 1980s, ADAPT gathered people with disabilities and demonstrated peaceably against the American Public Transit Association (APTA), the membership organization of transit authorities. ADAPT met APTA at annual national gatherings and regional meetings, where ADAPT members stopped buses by putting their wheelchairs at the front and back of the buses. Demonstrators chanted “we will ride” and called for lifts to be added to buses. By tying up transit and increasing public awareness of the issue on these occasions, ADAPT’s grassroots activism complemented the legislative lobbying that helped shape the ADA.

Fundraising was important for the demonstrators who, although among the poorest of the poor, were able to meet the challenge. Unable to find foundation assistance, they sold raffle tickets, sought funding from friends and used other methods to finance the trips. When the ADA was passed in 1990, it included requirements for lifts on all buses purchased after August of that year.

Today, ADAPT is empowering people with disabilities to advance reforms in the nursing home industry and make it possible for more Americans with disabilities to live at home rather than being forced into institutions. Despite ADAPT’s successes and worthwhile goals, many mainstream funders continue to frown on the organization’s tactics and to shy away from support. Added to these funders’ mindsets are the practices of United Way workplace giving programs, the federal government’s support of confining people with disabilities to nursing homes, state and federal control of funding for centers for independent living (CILs), and funding patterns that disproportionately favor health- and medical-oriented agencies. Taken together, these tendencies leave few funding opportunities for those nonprofit organizations that use different methods to advocate for fair policy changes.



Long-time advocate Barbara Toomer testifying in Washington last year to advance disability rights issues.

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CILs—nonprofits that provide peer support, information and referrals, advocacy and skills training—are vital resources for Americans with disabilities and are considered among the “safer” agencies for funders. Yet even they face unnecessary challenges to their effectiveness.

A CIL in Pennsylvania notes that when it accepts government funding, its hands are tied by federal and state government restrictions. The integrity of a project can easily be impaired if the agency does not concentrate on fighting for what the government thinks it should do. If an organization with 501(c)(3) tax status chooses to take government funds, this CIL suggests looking immediately for other funding sources. Rules change if the organization does something to upset the funders. In addition, government contracts and grants largely limit citizen participation. All funders need to assure that ordinary people are part of the process. A small staff with good organizing skills could bring people together with funding for travel, interpreters, lodging, attendant care and food. This could create real changes in policy and empowerment.

For United Way agencies, another challenge exists: They face a fundraising blackout period, sometimes as long as five months. This blackout period tends to offset or outweigh the benefits of receiving workplace funding through United Way campaigns. Since a receiving organization cannot operate raffles, dinners or other fundraising events during that period, its opportunity to raise funds is jeopardized.

Some CILs are also hurting for different reasons. An Erie, Pa., CIL receives \$3.5 million in pass-through federal Medicaid funding that is designated for attendant services only. The CIL has \$200,000 to run all other programs. Although its administrative costs for these services are small, its total income looks huge. When it applies for a grant, it usually cannot qualify because the pass-through funding, which it does not control, inflates its reportable total income. The director noted that even explanatory letters from the CIL’s accountant did not gain funding, as many foundations do not understand federal pass-through programs and do not make allowances for limitations on the use of income from other sources.

Small organizations also face problems in accessing the Combined Federal Campaign (CFC). Some belong to alternative funds that look to the CFC as a welcome source of income and program visibility. Yet participation in the CFC comes with strings that can overly burden small organizations. For example, the CFC demands an annual audit

for agencies with incomes as low as \$100,000; for small agencies with few employees, the \$5,000–\$6,000 cost of complying could be more than the donations that might come from federal employees.

A group from Pennsylvania was concerned because while funding is available for women, notably battered and abused women, civil rights advocacy for people with disabilities is felt to be “left-leaning” and therefore not eligible for funding. This same group finds that agencies that deliver “services” (e.g., CILs) get funded because they are seen as “safe,” while groups working for empowerment and civil rights are often denied general funding.

A Texas advocate recommends minimizing staff and maximizing involvement, saying, “It’s amazing what bringing folks to a state capital regularly during a session does to gain effective change.” But seed-money funding is needed to assist these emerging groups. A \$10,000 grant would allow for two technical-assistance organizing visits that would include board development, issues training, and outreach assistance, as well as taking members of the emerging group to national conferences to illustrate the power people with disabilities have when gathered together.

Finally, there is one more challenge that the future holds. Many advocates feel that the power of the people lies in youth leadership. Young people with disabilities are the leaders of tomorrow, but as yet there is little funding to build that potential for the long-term success of the movement for equal rights for people with disabilities.

Many nonprofits find funding sources limited, but particularly hard hit are agencies working so that one day Americans with and without disabilities will share the same civil rights. These organizations often face more funding challenges than do organizations focusing on medical and health issues. Clearly, such health issues are vital—but they should not obscure the need for adequate funding of the movement to ensure that all Americans, with and without disabilities, are treated fairly. In keeping with America’s dream of equal opportunity for all, people with disabilities only want to go where just about everyone else has gone before. Funders must now ask how best to help them get there. ○

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