

Old and **New Ways** for Developing Community Programs

By **Thomas Reinke, MA**

In these challenging times of cutbacks in public funding for social services programs, parents and grass roots organizations continue to make a difference in their communities with innovative initiatives that are enhancing the lives of people with developmental and physical disabilities.

In New York, a track team of speedsters with disabilities is racking up victories against mainstream teams and sending its athletes on to state and regional competitions. In Bucks County Pennsylvania, a coffeehouse is where young adults with autism develop solid peer relationships and hone their social skills, giving them the confidence and ability to be more successful in all aspects of their daily lives.

The techniques that have always worked in creating successful programs—passion, determination, and hard work—are still the only essential ingredients for success.

But also in these trying times a new model for community developed services and programs—social enterprises—is catching on. In New Jersey, a bookstore is linking its retail operations to an emerging job training program. And in northern California, two businesses created by United Cerebral Palsy of the North Bay are providing scores of jobs for people with disabilities.

Individuals and agencies that are interested in developing programs in their community should explore the social enterprises model.

THE TRADITIONAL APPROACH TO PROGRAM DEVELOPMENT

Rolling Thunder

The Rolling Thunder Special Needs Program, on Long Island, is a track team affiliated with USA Track & Field. It is an example of a program that was started through personal initiative. Its singular purpose is to provide opportunities for individuals with physical and intellectual disabilities to participate in all levels of mainstream athletics.

“I was always interested in sports and I wanted my son, Steve, who has cerebral palsy and intellectual disabilities to share my interests. We started in Special Olympics and that lasted for a few years,” says Steve Cuomo, Rolling Thunder’s founder. “But then it dawned on me that these kids have untapped potential and many of them want to be taught and compete in traditional programs.”

Steve Cuomo, the son, is 25; he started running when he was seven. Cuomo and his wife Beth have six kids, aged 30 to 13.

Cuomo is an outspoken advocate for athletes with disabilities to go up against typical individuals. He says many parents do not recognize the value of this opportunity. “Some parents may be too protective, or they may be concerned about being embarrassed that their child won’t do well. But what’s the worst thing that could happen? Nothing, really, if these athletes are in the race, they’ve already won.”

His advocacy led to the USATF asking him to take on the role of national chairman for the its committee for athletes with disabilities.

Rolling Thunder was officially formed in 2008 with 15 runners, many who came over from Special Olympics. The team’s objective of competing at the same time on the same fields with other teams apparently resonates with others; in just over two years the program has

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Harding says several things were important in getting the coffeehouse off the ground. “I listened closely to what the young adults wanted. Parents and professionals may think they know what is needed but those ideas can be wrong,” she says.

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While the coffeehouse has been successful, its future is somewhat uncertain, in part because of its dependency on county funding. Harding believes the program will need to find additional revenue sources and additional ways to prove its value.

SOCIAL ENTERPRISES – THE NEW MODEL FOR PROGRAM DEVELOPMENT

Words

Words is a two-year-old independent bookstore in Maplewood, New Jersey. In contrast to Rolling Thunder, it is focused on an entirely different goal, and following a very different path to success. Words is an example of a social enterprise, but it also is an example of the need to take a risk.

“As my son got older, my wife and I started to look to his future,” say Jonah Zimiles. “And my wife had the idea that we should start a vocational training program for people with autism.” The Zimiles’ son, Daniel, is 15.

That was in 2008 when the economy started collapsing. “There was a bookstore going out of business in our little town and Ellen came home one day and said we should buy it and run our training program out of it,” says Zimiles.

The Zimiles knew nothing about the book business but they figured they needed to take a risk and start some-

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grew to 163 members. It participates in USATF events on a par with other teams. “We took on 16 mainstream teams in one race, with sponsored teams like Nike and Reebok, and we finished in the middle of the pack,” says Cuomo.

Cuomo’s enthusiasm is one reason for Rolling Thunder’s success but he says the team’s progress is the result of the basic steps and activities that have always worked for creating opportunities for people with disabilities. One of those things is achieving some form of initial visibility. “We got 2 or 3 of these kids into the public spotlight, and then things started to happen.” Cuomo says no one will recognize or support you if they don’t know you’re there. He says that once people see you others will want to join, and still others will be willing to support your program. But he also says you can’t be afraid to ask for support. “I cry a lot on people’s shoulders, but that’s okay, because, bottom line, it’s for a good cause.”

The Bucks County Coffeehouse

The Bucks County Coffeehouse in Langhorne, Pennsylvania is an offshoot of a grass roots autism support group, Sharing and Caring of Bucks County, that was formed in 1991. Both organizations were started by Joyce Harding who has two children on the spectrum, John, 24 and Brittany, 17. The Coffeehouse is an example of the power of personal initiative, and the value of community networking.

Harding formed the support group in the days when there was almost no recognition of autism, and parents had to rely upon themselves. The knowledge and experience she gained through networking provided the basis for her to start working on a program for young adults, to fill the post high school services gap.

“I first reached out to parents in Sharing and Caring about what they thought their kids needed after high school. Then I went to the young adults themselves and listened to the themes and needs they expressed,” says Harding. “The idea for a coffeehouse came from the young adults. They resoundingly told me they didn’t want anything with the label of autism on it.”

Harding says they told her they wanted a place where they could be accepted unconditionally and have the opportunity to make friends among their peers. “There is a brotherhood and acceptance because they understand what it is to walk in the shoes of each other.”

She started work on this project in 2006 and the coffeehouse opened in a shopping mall in 2008. It is funded through the county office of behavioral health, and it is operated by a service provider agency.

Harding says the coffeehouse has made a difference. “It’s a place where they can take off the social armor they wear all day to protect themselves from being seen as different. At the Coffeehouse they can try new things and develop new skills, and I see where those new skills are making them more suc-

where. "Taking risk can be scary," says Zimiles, "but you also have to look at the risk of doing nothing, especially in terms of the future for our family members."

Words opened in January 2009 with Jonah as its manager. It has grown steadily in its two years of operation. In technical terms Words is a "social enterprise" - an organization that advances its social mission through business methods.

"We are a general bookstore and we are running a vocational training program within it," says Jonah. He stresses that for Words to be successful in job training it first must be a successful retail business. "We want the business to be able to stand on its own. We have to be customer focused; we need people to be our customers even if they aren't sympathetic to our cause." In that regard much of the effort during the first two years has been to build book sales.

But there are two other sides to the business. "We offer a friendly environment for families and we don't care if their children act differently. We want to create a model community of inclusion and we run programs like speakers and authors during autism awareness month," says Zimiles.

As for the job training program, Zimiles explains, "The hardest part of getting a job is having previous work experience. So, our plan is to train people in an apprenticeship or job coaching program, give them real work to do in a business environment, help them create a resume and connect them with employers."

The store offers job sampling opportunities to school districts. Students from special ed programs stock and recycle books. He plans to expand into job training for young adults who are out of school.

United Cerebral Palsy of the North Bay

There is increasing recognition that sustainable services for people with disabilities must be funded by sustainable busi-

nesses. And there are increasing examples of where that is occurring.

In wine country, Napa County California, United Cerebral Palsy of the North Bay (UCPNB) runs Wine Bev Services, a wine packaging business that in less than two years has grown from two to over 100 employees, all with disabilities. It competes head to head with other businesses and it pays its employees prevailing, not minimum, wages. Wine Bev Services has created a work environment, a production line operation, where employees can be successful in several different jobs regardless of the skills they had when they were hired.

Many of the management and business development functions are handled by UCPNB staff.

With one successful commercial venture in its pocket, UCPNB started an

entirely new business in October 2010, Gone for Good, a document destruction business. It employs 24 adults with developmental disabilities and will grow to 45 by June 2011. The agency received capital start-up funds from NISH, the national non-profit agency designated by the federal government to create employment opportunities for people with severe disabilities.

In the arena of social enterprises, UCPNB is a model for non-profit agencies wanting to become more self-supporting. •

Thomas Reinke, MA of Wallingford, Pennsylvania is a health care journalist, and parent of Mary Beth who has intellectual and motor disabilities. He is an Associate in the School of Population Health at Thomas Jefferson University and has served on the board of several disabilities advocacy organizations. He is involved with a group of parents that is working on new housing model based upon the social enterprises concept.

Lincoln Center

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