

Advocating for the disabled Bruce Darling has built the Center for Disability Rights into a \$26 million non-profit

By NATE DOUGHERTY  
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To describe the situation that met Bruce Darling and a group of some 400 protesters for disability rights who descended on Washington, D.C., would sound almost too clichéd to be true.

After walking and wheeling themselves into a busy intersection on Pennsylvania Avenue on a bright summer day to protest in front of the Office of Management and Budget, the group watched as black clouds moved in just as a representative came to talk to them.

"He took a look at us and said, 'Oh, it's going to pour so I guess you're all going to go home now,'" Darling says. "And as he was saying this, all 400 people started to put on their rain ponchos and got ready for the storm to come."

The 44-year-old Darling and the Center for Disability Rights Inc., which he co-founded in 1998, do not back down easily from a fight. The organization, which has a staff of 1,500 and annual revenue of \$26 million, advocates for the rights of disabled people and provides support services to allow them to live and work in the community.

Darling has taken on a range of issues—from the lack of lifts on public buses to advocating for more state funding for home health attendants—with an approach that mixes the cerebral with the attention-grabbing.

"We put out policy papers and talk about issues in a reasonable way, but sometimes people aren't rational and don't want to have a conversation," says Darling, who has been arrested more than a dozen times for civil disobedience. "When that happens, we do the direct action work to get people to the table."

More often than not, the direct action has been successful. During the state Legislature's one-day meeting in August to discuss the budget shortfall, CDR organized disabled protesters in a hallway near Gov. David Paterson's office.

When Albany Mayor Gerald Jennings went through the crowd to get to a meeting, a scuffle ensued between protesters and police. A member of the governor's staff stepped in to defuse the situation, and Darling was able to negotiate a meeting with Paterson to discuss the budget cuts.

Darling's diligent work ethic and willingness to stand up for the rights of the disabled resonate throughout the agency, says Christopher Hildebrant, director of advocacy.

The work has helped CDR grow and strengthen the relationships with elected officials needed to achieve its goals, Hildebrant says.

"I think initially there might be some trepidation from officials who may have heard something negative about us or read in the paper about our lawsuit with the transit authority," Hildebrant says. "But over time we have developed some excellent relationships."

Having joined the organization in 1999, one year after it was founded, Hildebrant recalls arriving at work early one Monday morning to find Darling already there, having worked through the weekend to install new computers.

A glance at CDR headquarters in Rochester would give an adequate picture of the non-profit organization's mission. On the side of the brick building facing State Street hang portraits of disabled persons in work settings and protests. At the bottom in block letters are slogans-"independence," "integration" and "civil rights."

The organization's work force-200 direct staff members and 1,200 attendants-lives the organization's mission of advocacy and service for disabled persons because a large number are disabled themselves. Darling has diabetes and face blindness, which means he is unable to recognize faces in the same way a color-blind person would be unable to recognize colors.

Eugene Spinning, president of the CDR board, joined after receiving services from the organization.

"After they helped me get out of a nursing home, I went to talk with them about things I saw that could be done differently, and my involvement grew from there," Spinning says.

The organization, which started out with a \$200,000 budget and operated out of a single room, now has close to \$26 million in revenue each year and operates offices in Geneva and Albany, with a new office set to open in Steuben County.

The bulk of the organization's income comes in the form of Medicare and Medicaid payments. Most of its expenses come through its self-directed personal assistance program, which allows people with certain disabilities to select aides who will assist them in their care.

#### CDR's history

Darling has long known the struggles faced by the disabled, especially before the Americans with Disabilities Act.

After his grandfather lost both legs to diabetes, Darling helped him go to the Department of Motor Vehicles and get a new license to drive using hand controls. The building was not accessible by wheelchair, so the two ended up waiting in a doorway for hours before someone could come to help them.

The situation stayed with Darling, but it was ultimately his work with the disabled while an employee of the Monroe County Library System that tilted his career path toward advocacy. He worked in the literature department, learning how to use a machine that reads printed words to blind people and studying magazines and literature on disabled life.

"I was reading a magazine called Disability Rag, and it had an article about how one of the airlines required wheelchair users to be catheterized on flights," Darling says. "I was in my young 20s and I said, 'Can you believe they require wheelchair users to be catheterized?' And everyone just looked at me in horror, shocked that I was talking about this. That's one of the things that stuck with me, to see how unfair life was for the disabled."

Darling moved into special services for the library, developing programs for disabled patrons. He would give talks on the services the library offered, and after officials from the Rochester Center for Independent Living saw one of his presentations, he took a job there, evaluating agencies and organizations for accessibility.

While working there, Darling formed a group to advocate for putting lifts on buses, allowing wheelchair users to ride without needing a companion. After succeeding

in getting lifts put onto all Regional Transit Service buses, Darling says, the group had a sense of aimless energy waiting to be directed to other causes.

"The group just stopped and said, 'OK, we did that. Now what do we do?'" Darling says. "One of the biggest issues people were confronting was the lack of attendant services and community-based services, so we changed our name to the CDR and started working on that issue."

In its early days CDR was a small organization based in a single room of a building at Lake and Ravine avenues, an intersection where car crashes were so common that the staff barely took notice.

It grew in spurts from there, increasing its budget from \$400,000 to \$800,000 to \$1 million. The staff also grew steadily as it moved into a building on State Street and then to the former Win Fa market at the corner of State and Jay streets.

"For a long time I knew everyone who worked for us and everyone who received services," Darling says. "Then one day I was doing some holiday shopping and I thought 'There are probably people here at this mall who work for me, and I don't even know it.' That made me realize how big we were getting."

Darling lives in Greece with partner Tom Christensen; they spend free time making renovations on the home they share. Darling says he does not have much time for other hobbies or activities as his work with CDR consumes him.

#### Its issues

Advocating for consumer-based services, the first priority of CDR, has emerged as a major initiative. In 1993 Darling wrote a 200-page evaluation of community-based personal assistance services in Monroe County and founded a program in which consumers have more control over services.

The paper, "Early to Bed/Late to Rise," became the basis for a statewide CDR program that allows agencies to send out attendants to assist disabled individuals with their daily tasks. Attendants are more flexible and cheaper than home nursing care, Darling says.

"It's an incredible program because it gives people so much more control over their schedule, because the attendant is committed to working with you and your needs," Darling says. "The training requirements are also a lot looser, so instead of going through 40 hours on how to work with some generic person, they work just with the individual receiving services."

Program consumers have more power to choose who administers the service, and family members can be trained to serve as attendants. One of CDR's board members, who works in telecommunications, helped develop a telephone bank modeled after a dating hotline. Callers can match up with attendants and use a voicemail offered through the hotline instead of giving out a home telephone number.

"We found a lot of other places were giving out typewritten lists of available attendants, but we found by the time you print it out it's already out of date," Darling says.

The program also offers year-after-year savings in Medicaid, Darling says. A disabled individual receiving home nursing services could pay roughly \$32 an hour, but Darling says attendants can work at half that cost. With state legislators and the governor

looking for any ways to cut spending and make up for budget shortfalls, Darling says the time is right to grow and expand the program statewide.

"They like to solve problems with a quick fix and then end up going into the next year with a multibillion-dollar deficit," Darling says. "This would end up saving a lot of money for them. We have been having a lot of discussions with the state Department of Health about this lately."

#### Integration mission

One of the organization's flagship issues came to Darling's attention through a relentless service recipient nearly a decade ago.

The man called time and again to ask what the organization was doing to help get disabled and elderly people out of nursing homes and back into the community, but Darling says his responses were usually excuses.

When one of the calls caught Darling "in just the right mood," he vowed to look into the issue.

"I told him, 'You're right. We're going to start this tomorrow,'" Darling said. "And we did."

The idea behind the program is that by getting more disabled and elderly people back into the community, CDR can give them the independence they want while also reducing their cost for care. CDR helped create the Nursing Home Transition and Diversion Waiver, which uses state Medicaid funding to help individuals move from a nursing facility into the community or prevent institutionalization.

The program has had detractors during the last 10 years, many of whom were interested in keeping the health care system status quo, Darling says.

"We fought the assumption that old people need to go into a nursing facility and people with disabilities need to be taken care of," he says. "There was also a lot of mythology about services being expensive and the idea that New York already provides this range of services, so people have everything they need.

"Then there was also just fear, people saying, 'You can't do that.'" Many of the 5,000 people who have made the transition are those who had become lost in a gray area between health care providers and relegated to nursing homes as a solution. One of the organization's earliest organizers, a Vietnam veteran suffering from multiple sclerosis, was sent to a nursing home because he uses a ventilator and the hospital in which he was staying had no service category for him.

"We're in the process of getting him set up to go back home, and we're really excited about getting him out," Darling says.

Even Spinning, the board president, found himself in a nursing home after confusion about his medical coverage. Unable to struggle through the bureaucracy needed to leave, Spinning would wake up in the morning and drive himself home, only returning to the nursing home at night to sleep.

Like the consumer-directed service model, this program offers the state an opportunity to find the kind of institutional Medicaid savings legislators desperately are seeking, Darling says.

"Think about it like you're going to a restaurant," he says. "It's like ordering a meal that comes with every course, and even if you don't want dessert you're going to get it. In this case recipients of care are only getting the services they need."

Costs for the program are higher when people first move into the community but decline steadily as they become more acclimated and develop relationships, Darling says. CDR-and Darling in particular-have worked with groups nationwide to roll out the program. Each state comes with its own unique laws and difficulties, but Darling says it is rewarding to see the idea that started with a single persistent individual become a dynamic means to empower the elderly and disabled.

"I like to say because Charlie Smith made this phone call it turned into all these ripples of change across the country," Darling says.

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