

LIFELINE OF HOPE



For people with intellectual and developmental disabilities

FOR MORE THAN 60 YEARS, THE ARC HAS HELPED PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES LEAD HAPPIER, HEALTHIER AND MORE FULFILLING LIVES.

IDNICAL TWINS ANNIKA AND MAYA ADRIAN-HAGE WERE BORN IN 2003 with such a rare genetic disorder that doctors didn't even know what they had. They didn't move or display facial expressions. Their muffled cries were barely audible. The girls spent the first four months of their lives in the hospital overcoming illness after illness before doctors could stabilize them enough for their parents, Bob and Odette, to finally bring them home to their New Jersey residence.

"That's really when our odyssey began of trying to figure out what to do for support and services for these girls," says Bob, a small-business owner who would carve out large chunks of time to find help for them. "You cannot imagine in your wildest dreams what an overwhelmingly difficult task it was—emotional, physical, financial. There was no one reaching out, no one explaining how to connect to support and services. I was progressing at a snail's pace until I connected with The Arc four years ago. They worked magic."

With more than 140,000 members affiliated through more than 700 chapters throughout the U.S., The Arc has been a lifeline for many of the 7 million people in the country with intellectual and developmental disabilities (I/DD)—such as Down syndrome, fragile X, autism spectrum disorder and cerebral palsy—and their families. It's the largest organization of and for people with I/DD, and the ninth-largest charity federation in America, right behind United Way, with total revenue of \$3.6 billion.

But despite its reach and size, chances are that many people

reading this are hearing about The Arc for the first time. "The Arc is a grassroots organization that has developed from the ground up, so it's never really devoted a lot of resources to promoting the brand of the organization at the national level," says CEO Peter Berns, who works with a 24-member national board that guides The Arc's work. "That's something we're doing now more intensely. Ultimately, it's about having more impact on behalf of people with intellectual and developmental disabilities. The Arc is, at its core, a human rights organization, and it is also the largest provider of services and support for people with I/DD."

The Arc's services include early intervention, health care, education and family guidance, as well as employment preparation and assistance, independent-living skill training and recreational activities for about a million people each year. The Arc is also the foremost advocate for people with I/DD and their families at both the state and national levels, influencing legislation, policies and funding for disability programs and services.

"One of the interesting things about The Arc as an organization is that it's led and staffed by parents and family members of people with disabilities and people with disabilities themselves," says Berns, who has been CEO for three years and was recently appointed to President Obama's Committee for People with Intellectual Disabilities. "They have



Dynamic duo: Annika and Maya have blossomed into happy 8-year-olds thanks to The Arc programs.

Helping people who have intellectual and developmental disabilities live independent lives—preparing a home-cooked meal or experiencing a day of therapeutic horseback riding—is what The Arc is all about. **BELOW:** Andy Attala is enjoying life as an artist in Medford, Ore. **BELOW RIGHT:** Bryce Williams and Jay Martin reading with teacher Diane Tucker at Goldman School in Louisiana.



extraordinary passion, so there's a tremendous sense of responsibility that goes along with this job."

STILL IN THE SHADOWS

A SMALL GROUP OF PARENTS AND CONCERNED CITIZENS founded the organization in 1950—11 years before President John F. Kennedy called attention to people with I/DD, like his sister Rosemary. At that time, many lived in the "shadows," locked in institutions with little chance of ever becoming part of society. With the advocacy of The Arc, the country has made huge progress in helping people with I/DD become rightful members of our communities. In 1967, more than 187,000 people with I/DD were living in state institutions. Today, there are less than 34,000. And whereas schools once locked their doors to keep children with I/DD out, today every such child has the right to a free and appropriate public education.

But the situation is far from ideal, which is why on its 60th anniversary The Arc commissioned a 2010 survey, "Family and Individual Needs for Disability Supports," to assess the current state of people with I/DD. The resulting report (which may be downloaded from thearc.org) sadly shows that we've fallen well short of JFK's vision of society. The economic crisis and budget cuts have drastically reduced services, according to 62% of respondents, while 43% report that schools have cut back on programs like physical, occupational or speech therapy. "Our biggest

concern," says Berns, "is that the government not try to balance the budget on the backs of people with intellectual and developmental disabilities who are among the most vulnerable of our population."

They're people like Leonette Branham of The Arc's San Francisco chapter, where health

advocates help "Leo," 55, who's a diabetic, live an independent life in the only apartment building in the city for people with I/DD. "It's just part of being human," says Leo's advocate, Jennifer Dresen, of community-based living. "You just want to be able to make as many choices as you can for yourself. In institutional living, choices are taken away. You don't get to decide what you eat, or what you do. Your life is less your own."

Fortunately, corporate sponsors such as Mutual of America are there to help people like Dresen who do so much to help others. "The Arc's mission to promote and protect the human rights of people with intellectual and developmental disabilities throughout their lifetimes is truly admirable," says William Rose, executive vice president and chief marketing officer. "And succeeding in this mission would not be possible without the selfless dedication of its employees throughout the country."

"Mutual of America could not be more proud of our long-standing relationship with The Arc and hundreds of its chapters nationwide," he adds. "As a retirement plan service provider, we remain committed to helping their employees—who are so focused on serving the needs of others—save for their own retirement and achieve their long-term financial goals."

As for Annika and Maya, today they are thriving, happy 8-year-old girls who attend public school and love listening to music and playing in the backyard. They're flourishing in large part because of The Arc, which has provided a community of support and direction. "Because of The Arc, they have achieved a big percent of what their potential is," says their father, Bob, who is nevertheless concerned for their future. "The storm clouds are all around us. It's incredibly bleak because of the fiscal crisis. That's why The Arc is so important. They see these issues and are fighting all the time to bring more equality for people with I/DD."

—Tom Cunneff