



## **The Arc's Chapters – Making the Future More Secure for Families Across the Country**

**By Marty Ford, Senior Executive Officer, Public Policy, [The Arc](#)**

Aging parents of adults with intellectual and developmental disabilities (I/DD) often worry about what the future will hold for their sons and daughters, and many families need support and guidance to plan for the future. Recognizing this growing need, The Arc decided to take action. Through a grant, The Arc is establishing the Center for Future Planning.

The goal of this project is to support the estimated 600,000-700,000 families in the United States in which an adult with I/DD is living with aging family members and there is no plan for the individual's future. The Center will empower aging caregivers and their adult sons and daughters with I/DD to plan for the future, providing families with information, resources and practical assistance in person-centered planning; guardianship and supported decision-making; housing and residential options and supports; special needs trust (SNT) and representative payee services; financial planning; and personal care and independent living supports.

With nearly 700 chapters across the country, The Arc has many state and local chapters that support families through future planning. One critical aspect in the planning process is establishing a special needs trust (SNT) for the benefit of the individual with I/DD.

In general, there are three types of SNTs:

- A first party SNT is established with funds belonging to the individual with I/DD.
- A third party SNT is created with funds belonging to someone besides the beneficiary—family members or friends.
- A pooled SNT, administered by a nonprofit organization, consists of “sub-accounts” funded for numerous beneficiaries, combined for the purpose of cost-effective management. They can be either first party or third party trusts.

If the individual with I/DD is a beneficiary of Medicaid and/or Supplemental Security Income (SSI), then specific rules must be followed for eligibility to remain intact. Families typically work with attorneys (such as members of the Special Needs Alliance), banks, or other financial institutions to create a first or third party SNT, whereas pooled trusts are administered by non-profit organizations

Learn more about three amazing chapters of The Arc and how their work is making the future more secure for families they serve.

### **The Arc of Indiana:**

The Arc of Indiana Master Trust provides educational resources, as well as pooled trusts, and follow-up care for beneficiaries.

“People need to have as much good information about special needs trusts as they can so they can make the best decision for themselves and for their families,” said Melissa Justice, Trust Director at The Arc of Indiana.

A non-profit trustee, such as The Arc of Indiana, may provide more flexibility and lower fees than many banks. While many banks require minimum deposits of \$300,000 or more, The Arc of Indiana requires a minimum of \$30,000. Another benefit families find when they turn to The Arc of Indiana is the knowledge of regulations for SSI, Medicaid, SSDI, and other means-tested benefits.

“Once families make the decision to use our trust, they always find relief,” Justice said.

As Justice has seen firsthand, setting up a trust for a loved one can provide a caregiver indescribable relief in difficult times. That was the case for one family she worked with. The family had known about The Arc Master Trust for several years, but didn’t make the effort to start one of their own until their mother was diagnosed with cancer.

The mother who set up the trust shared her thoughts saying, “I don’t know why I didn’t do this before. I’m so relieved that we are doing this.”

### **ACHIEVA:**

The ACHIEVA Family Trust, established in 1998, has made it a mission to find new ways to support families in the Greater Pittsburgh area as they begin future planning for their loved ones. This year they will begin a new and exciting project.

Through a grant from the United Way of Allegheny County, ACHIEVA will expand its support by beginning a “Future Planning for Families” project. With it, over 80 volunteers will serve 1,500 individuals with disabilities and their families over a three- year period.

In addition to providing trusts with lower fees without compromising government benefits, the project aims to provide quality information for caregivers as well as a comprehensive online planning guide to equip families for the future. The project also aims to educate law students about how to approach future planning and will establish a referral network of attorneys and other legal resources.

To reach people from all different fields, ACHIEVA will also initiate a public awareness campaign called “Ask the Disability Expert” to be aired on a local radio station.

“In the history of The Arc we have always been on the cutting edge of advocacy. If we are a typical company doing special needs trusts we would function like a bank or financial institution, but we are a chapter of The Arc. It is because of who we are and our advocacy that we are doing what we do and we know this is a very important project for our community,” said Maria Smith, Vice President, ACHIEVA Family Trust.

### **NYSARC:**

NYSARC, The Arc’s State Chapter in New York, has one of the largest pooled trust programs in the United States with over 7,000 beneficiaries.

What makes it unique is that the trusts are available to individuals with any type of disability, including those with mental illnesses or physical disabilities.

The organization can easily open a trust for an individual within a week, but in emergency situations, they can even open a trust within 24 hours. Services are not only quick and readily available; they are also specialized to meet individual needs.

“We know that every person is an individual and every person has specialized needs, so we provide specialized services,” said Heidi Flatt, Chief Operating Officer of NYSARC Trust Services.

*The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes. SNA is partnering with The Arc to collaborate on providing educational resources, building public awareness, and advocating for policies on behalf of people with intellectual/developmental disabilities and their families.*

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