

## Best Practices in Pooled Trust Programs

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Pooled trusts, usually operated by non-profit organizations, are used by families and others to provide financial care for the person with intellectual disability (ID) or other disability. In lieu of establishing an individual trust account for a son or daughter, families “pool” resources with other families in one trust. The organization then manages and invests the trust as a single fund which reduces administrative fees as there is only one account, and increases the total amount of principal for investments. Beneficiaries then receive earnings based on their share of the principal. Some organizations also operate a type of trust that an eligible individual with a disability can fund with his or her personal money. Pooled trusts allow families with smaller amounts of money to use trusts (in lieu of bank trusts that usually require larger accounts) and are



usually managed by an organization that is operated by or affiliated with a disability group.

Pooled trusts are especially beneficial to people with intellectual disabilities receiving services through Supplemental Security Income (SSI) and Medicaid. SSI and Medicaid are usually means-tested, meaning the person's assets cannot exceed a certain amount, and the person must usually contribute toward their cost of care with the proceeds from their earnings, SSI or Social Security Disability Insurance checks. Many of these individuals are then left with only a small personal care allowance (as low as \$30 per month in many states) for clothing, toiletries and related items, that parents often subsidize because the amount is grossly insufficient. If a parent then dies and leaves their son or daughter an inheritance to help cover these costs, the inheritance will likely be considered an asset and the heir will be charged a full "cost-of-care" charge, which would quickly deplete this inheritance meant as supplemental funding. Pooled trust usually do not impact the individual's SSI and Medicaid in this manner as the trust restricts distributions to certain limits or usage. This helps to ensure that an inheritance to provide supplemental income can will not be lost.

Aside from fund management, pooled trusts often provide a variety of other beneficial future planning services. Most will assist families with information about guardianship and alternatives, referral to professionals, information on services and other legal and non-legal assistance. (Hartley & Stewart, 1993; The Arc of Indiana, 1990).

### **Study Purpose and Objectives**

The aims of this project are to increase understanding of quality practices in pooled trust programs; to aid families in using trust programs or alternatives; and, to increase the family's ability to develop effective future plans that address financial, legal and service/support areas.

1. What information do families and individuals need to make an informed choice about using pooled trust programs?

2. How are pooled trust programs organized and what services do they offer?
3. What are the experiences and levels of satisfaction of families who have used pooled trust programs?

### **Sample Population and Methodology**

The Arc conducted three studies:

*Study 1.* A forum of trust program representatives, parents who have developed a financial plans and legal/financial planning experts was convened to begin the process of identifying best practices for pooled trusts. Through a consensus process, participants identified information, practices and strategies to increase the family's knowledge and skills in using trust program services (or alternatives) and program quality (e.g., advantages/disadvantages of a pooled trust; strategies to determine adequate trust amount; questions and methods families can use to identify program quality).

*Study 2.* Trust programs were surveyed by mail to elicit the following: structure of program (separately incorporated, administered by another organization); governance; quality assurance mechanisms (internal, external evaluations); populations served (people with ID only, cross-disability); geographic locale served; service monitoring; state-specific regulations that impact program; type(s) of trusts provided; investment minimums, fee structure; disposition of trust remainder upon beneficiaries' death; and, steps undertaken in developing their program. This information was used for background in producing the pooled trust document.

*Study 3.* The Arc conducted a survey of families who have used pooled trust programs or conducted other financial planning to determine their experiences and satisfaction with these programs or other planning methods used. Questions included: type of financial plan used (pooled trust, individual bank trust); reason(s) for choosing plan; obstacles to planning resources (e.g., lack of information, lack of resources); satisfaction level with program/plan; methods or strategies used or helpful in making decisions (training, materials, professional's assistance); family members participating in decision-



making (including relative with disability); and demographic information. The survey was disseminated through The Arc's newspaper to its members.

### **Data Analysis**

Data analysis responded to research question #3: *What are the experiences and levels of satisfaction of families who have used pooled trust programs?*

### **Findings and Implications for Research and Practice**

Families' needs for information on guardianship and alternatives, trusts and planning for services and supports are well documented. Many fail to engage in timely future planning were the primary respondents to the survey in study 3. Seventy-four percent of the 223 respondents had a financial plan in place for their family member with a disability (Davis, 2001). Only 5% of these respondents used a pooled trust.

Many of the 26% who had not developed a financial plan assumed that such planning for the relative with a disability is just for people who are wealthy. This supports the importance of educating families about options other than a trust established with a financial institution. The use of a pooled trust is one option. However, it is not universally available, as only 22 states are known to have pooled trusts operating, and not all of these are available to families statewide. Families reported that they receive much of their information about future planning from literature provided by chapters of The Arc and other agencies. The development of *The Family Handbook on Future Planning* helps build the capacity of families to "take control" of planning for their family member's future, a complex area that intimidates families. It can guide families to develop a future plan for their sons or daughters with cognitive, intellectual or developmental disabilities that provides personal, financial and legal protections for these individuals after the parents either die or can no longer provide care or support.

Another beneficial outcome of the project's work is in the area of pooled trusts. The project's findings led a meeting of experts within The Arc to review concerns and issues related to pooled trusts. As a result, the group developed a Recommended Policy for Pooled Trusts Administered by Chapters of The Arc. Chapters with pooled trusts now have formal guidance on ethical operation of such trusts.

### **Publications and Products**

The Arc of the United States. (2002). *Pooled Trust Programs for People with Disabilities: A Guide for Families*.

Davis, S. (2001). Family survey sheds light on financial planning trends. *Insight*. The Arc of the United States, vol. 51, no. 4, pp. 16-17.

Davis, S., Ed. (2003). *A Family Handbook on Future Planning*. The Arc of the United States and the RRTC on Aging with Developmental Disabilities.

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