



## NEXT STEPS TO CONSIDER AFTER SETTING UP A SPECIAL NEEDS TRUST

Congratulations on establishing a Special Needs Trust. This will be an important resource to help address your son or daughter's financial needs related to medical and personal care, preferences and life enrichment opportunities while protecting his or her benefits. Following are some additional steps to consider in planning, based on lessons learned by families and the advocates involved after parents are gone.

**STEP 1: Assure your relative's access to the Special Needs Trust (SNT) after you are gone. Prepare a Letter of Intent to clarify your wishes, and consider how your Trustee will learn of your relative's financial needs.**

**A) Prepare a Letter of Intent to guide your trustee and others on how you envision the Special Needs Trust will be used for the benefit of your son or daughter, your perspective on his or her needs, other resources, and hopes for the future.** The Arc of Frederick County offers a comprehensive Letter of Intent template. [http://arcfc.org/what\\_we\\_do/future-planning.html](http://arcfc.org/what_we_do/future-planning.html)

Be sure to include instructions on how you prefer the money in your child's trust to be spent. Examples include:

- i) supplement government benefits by paying for recreational activities that my son/daughter chooses;
- ii) cover any medical/dental expenses not covered by healthcare insurance;
- iii) provide my son/daughter with up to date assistive devices that will allow him/her greater accessibility to community resources and participation;
- iv) augment funding for additional support staff if necessary, for example a companion if hospitalized.

Avoid being too specific, as your son/daughters preferences and needs may change over the years. If there are specific things you do not want the trust to pay for, include instructions about this also. Plan to update your Letter of Intent periodically and provide copies to your executor, trustee, advocate, and key people supporting your relative.

Although a Special Needs Trust is discretionary and a Trustee is not legally obligated to follow a letter of intent, they are more likely to do so if you help them understand your relative's needs. Some parents partially fund a Trust while they are living to see that all runs smoothly.

**B) Consider how your trustee will learn of your relative's financial needs.** A local family member serving as trustee can visit and attend meetings, but bank and attorney trustees typically respond to funding requests.

The "team" (your son or daughter, family members if any, residential and vocational providers, Coordinator of Community Services) can identify financial needs throughout the year or at the

annual planning meeting, but service providers may overlook a Trust when planning, for several reasons:

- i) One in three residential staff change every year, so eventually those working with your relative may be unaware of the trust.
- ii) Teams are accustomed to planning without financial resources, since the vast majority of people in services do not have a Trust.
- iii) Team members may not understand the purpose of a SNT or how to access funds. They may consider money a private matter so await a Trustee to inquire about needs.

Possible strategies:

- (1) Provide written instructions for the residential agency and Coordinator of Community Services files, about the purpose of the Trust and how to request funds. Ask that the Trustee contact information be noted in the Individual Plan (IP) once the SNT is funded.
- (2) Provide a sample letter to your trustee to periodically send to the Coordinator of Community Services and residential service provider, to review the purpose of Trust, how to request funds, and inquire about current needs. [www.bytheirside.org](http://www.bytheirside.org)
- (3) Involve a private advocate to visit, monitor, advocate, and provide updates including financial needs to a trustee or distant sibling. By Their Side is a non-profit, family-funded advocacy organization started in 1965 by parents to provide advocacy after they were gone. Advocates monitor based on individual preferences and needs, parent wishes, and letter of intent, and can serve as liaison with Trustee. Each year, family or trustee decides the frequency of visits and monitoring contacts needed. [www.bytheirside.org](http://www.bytheirside.org)

## **STEP 2: Plan for your son or daughter's eventual transition into a home without you. Explore residential support options.**

**A) The Maryland Developmental Disabilities Administration (DDA) offers residential support for those in urgent need.** Apply for DDA services now so you have time to locate necessary documents, and so your relative will be approved and on the Waiting List when services are needed. <http://dda.dhmdh.maryland.gov/SitePages/howtoapply.aspx>

**Once on the DDA Waiting List, Contact your Coordinator of Community Services (Resource Coordinator) as soon as you foresee your need for services is becoming urgent.** Funding for DDA services is reserved for individuals in urgent need, such as situations posing risk to health or safety, for example change in caregiver health limiting ability to continue care, inability to manage individual behavior, etc. Keep a list of examples and documentation to support your request.

**Meanwhile, begin to identify a residential service provider.** The DDA website includes a list of licensed providers. Review provider descriptions and websites to identify providers that offer the type of services needed and whose beliefs about service provision match your own. Licensure records including any past allegations are located at the Office of Healthcare Quality

and are public record. While most providers are unable to schedule interviews until DDA has authorized funding, some will provide parent references or add you to their mailing list.

**After funding is approved, schedule interviews with your top 3 or 4 providers.** Consult with your Coordinator of Community Services for suggestions. Involve your son or daughter in the selection of their new home as much as possible, including home tours and interviews with potential housemates or new staff. A comprehensive list of interview questions to be tailored to your needs is available from the Arc of Frederick County, [www.arcfc.org](http://www.arcfc.org).

If your preferred residential provider does not have a home available, they may be willing to start a new home if your Coordinator of Community Services can network and identify other newly funded individuals seeking similar housing, who might like to consider being roommates.

**B) If Section 8 housing is desired, apply for a Voucher as early as possible.** Individuals with a higher level of independent skills may not receive full residential funding from DDA, or may choose to live in a more independent setting. Section 8 vouchers reduce the rent in participating housing complexes. The waiting list in some areas is 7 or more years.

**C) Is home ownership an option?** Parents may purchase a home through a HUD loan for their son or daughter, or provide an option for the Special Needs Trust to make a down payment to purchase a home/condo.

Other parents have planned to leave their home to the SNT, so their son or daughter can maintain the supportive relationships and participation within their immediate neighborhood and community. If funded by DDA, a provider agency can provide up to 24 hours/day of Personal Support in a Trust-owned home. Housemates can pay rent to the Trust, which can contribute to the cost of home maintenance.

**D.) Is your plan for your son or daughter to move in with a sibling?** This option requires significant advance planning with the sibling, including a plan for continued support and supervision while the sibling is at work. Some considerations:

- i) When a parent as caregiver is unable to continue care, the DDA is likely to prioritize and fund residential services. If your son or daughter moves in with a sibling who later wishes to pursue DDA services, DDA will evaluate need based on the sibling as caregiver.
- ii) If the sibling moves out of state, funding for services such as in home supports will not transfer. Application would be made for similar services in the new state; most states have waiting lists.

**STEP 3. Prepare a sibling, relative, or friend as next generation advocate.** Unfortunately some siblings report they were never actually asked, were not adequately prepared, or were left to make residential arrangements without the support of their parents.

- A. Have a conversation to explain what is entailed and ask his/her/their willingness to check in on your son or daughter, help if needed, and attend the IP meeting, after you are gone. Explore reservations and line up resources to assist. For example, if a sibling is not prepared to handle finances which can be time involved, let them know

the residential agency can serve as representative payee and you will find another trustee.

- B. For a larger family, consider how your advocacy role may be shared by several siblings. One family held a series of meetings for siblings to explore strengths and comfort levels as they divided up tasks. A distant sibling serves as trustee while one local sibling visits regularly and the other attends meetings. This plan carries forward through time rather than one person becoming overwhelmed or each situation requiring negotiation of roles, which can be a source of contention.
- C. Plan learning opportunities such as attendance at Individual Plan meetings and doctor appointments related to significant medical diagnoses, so you can demonstrate how to work with the team and explain the process.
- D. Create an organized filing system for your relative's important documents, and keep notes on to each contact including date, person contacted/ph number, information learned, questions, and planned follow up. This can provide background and help the next advocate to pick up where you left off. A Personal Information Notebook index is available at [www.bytheirsideside.org](http://www.bytheirsideside.org)
- E. You may wish to retain a private advocate to serve as an ally, especially for siblings whose work may take them out of Maryland. [www.bytheirsideside.org](http://www.bytheirsideside.org)

**STEP 4. Prepare a written narrative to smooth your son or daughter's transition into a new home, identifying important information to help new caregivers and those coming after to understand your relative's preferences and needs.**

A transition to a new living situation may be challenging for your son or daughter as he or she experiences a new living environment with housemates and staff, and a new routine. The more information you can give the future residential provider about your relative, the better. Whether or not a provider has been identified, write down information to share later. This will ensure information is available even if you can't be there yourself, and can be used when staff change over time.

Ask yourself, "What will help my son/daughter cope with the transition?" For example,

- Visits from family members
- Comfort items big and small
- Continuing routines of daily living
- Neighborhood familiarity
- Concrete plans to continue preferred activities and relationships
- Psychological support from professional counselors
- Tips to help staff support your relative if anxious, unhappy, or angry

It is important for the supporting agency to know as many of your relative's preferences as possible. For example:

- Preferred breakfast foods? Other meals?
- Daily routine and important rituals or traditions?
- Favorite kinds of movies?
- How does your relative want their privacy respected?

The Individual Profile Completed with Family or similar document can help assure your relative will continue to benefit from your knowledge and strategies. [www.bytheirsideside.org](http://www.bytheirsideside.org)

Contact information will be needed, such as

- Family contact in an emergency, including contacts for the future.
- Trustee
- Medical professionals
- Vendors servicing a wheelchair or providing orthopedic shoes, for example
- Other family relationships and friendships to be maintained

Finally, original or copied legal documents should be prepared, to be shared with a provider at the appropriate time. These items include, but are not limited to:

- Birth certificate
- Social Security card, insurance cards, identification card
- Trust and guardianship papers.

See Personal Information Notebook Index for expanded list. [www.bytheirside.org](http://www.bytheirside.org)

### **STEP 5. Consider how to help others to support your son or daughter to grieve your loss after you are gone.**

The loss of parents may be the greatest loss your son or daughter will experience. Over time, you have learned how your relative expresses grief and what can help. You may use certain phrases to explain that someone has died and will not return, or may discuss religious beliefs about where they may be now. Residential staff, advocates, and others will be best prepared to support your relative if you share this information in writing, including what has helped your relative to cope in the past.

If your son or daughter is an only child living with a residential agency and anticipates your visit each week, consider introducing an additional visitor such as a close family friend, or if involved, a By Their Side advocate. With another person to visit on occasion, in the future when you are gone, your relative may be comforted by visits with someone else they know.

A wide range of grieving resources are included in **Planning for the Future of an Only Child (and Those with Siblings)**, [www.bytheirside.org](http://www.bytheirside.org) For example,

**“Supporting people with learning disabilities through a time of bereavement and loss”** by Cristina Gangemi, describes how a person with a disability was included in a supportive role such as greeting guests and offering refreshments, when a close family member was in home hospice, and support that was provided process events and feelings including discussion of religious beliefs and creation of a memory scrapbook.

<http://www.rcpsych.ac.uk/pdf/CGangemiSupporting.pdf>

A “Social Story” tells a story of importance to a person with a developmental disability, addressing facts, beliefs, and emotions to help him or her cope with a change in life through repeated readings (as desired) and discussion. Online resources provide the opportunity to tailor a Social Story for your relative about the loss of a loved one using personal pictures, familiar explanations, and comforting beliefs. An example:

<http://www.pathfindersforautism.org/docs/social-story-about-death.pdf>

## **STEP 6. Consider how to carry your family story forward.**

Your son or daughter may wish to hear and enjoy family stories after you are gone, even if a relative is not available to tell the story. Creating a photo album or memory book with your son or daughter, or preparing one for them, which can later accompany them to their new home, can help serve this purpose. Labeling photographs with names, relationships, and descriptions of important events, including favorite activities and vacations, traditions and familiar family stories, allows staff or visiting advocates to talk with your son or daughter about their past as well as gain insight into activities they may enjoy again. Advocates report individuals often enjoy hearing family stories, and may smile in recognition when a name is associated with a photograph.

By Their Side families asked for assistance with planning for the future of an only child. We wish to thank the dedicated members of the parent and multidisciplinary focus group that met to explore the issues and related resources.

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This document is available at [www.bytheirside.org](http://www.bytheirside.org) for easy linkage to resources.

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