



NEXT STEPS TO CONSIDER PLANNING BEYOND THE SPECIAL NEEDS TRUST

A Special Needs Trust will help address your son or daughter's financial needs related to medical and personal care, preferences, and life enrichment opportunities, while protecting their benefits. An ABLE Savings Account can be used for disability related expenses with similar benefits. This guide suggests planning steps to consider in addition to financial planning, based on the experiences of advocates and family members involved after parents are gone:

- Assure your relative's access to the Special Needs Trust 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.
- Plan for your son or daughter's eventual transition into a home without you. Explore residential support options.
- Prepare a sibling, relative, or friend as next generation advocate.
- Develop a written narrative to prepare current and future caregivers to respond to your relative's preferences and needs.
- Prepare others to support your son or daughter to grieve your loss after you are gone.
- And, consider how to carry your family story forward.

STEP 1: Assure your relative's access to the Special Needs Trust after you are gone.

A) Prepare a Letter of Intent to guide your trustee and others on how you envision the Special Needs Trust will be used for 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

A Letter of Intent includes instructions on how you prefer the money in your son or daughter's trust to be spent such as

- 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 relative's preferences and needs may change over the years. If there are types of things you do not want the trust to pay for, include instructions about this also. Plan to update your Letter of Intent periodically as needed and provide copies to your executor, trustee, advocate, and key people supporting your relative.

Because a Special Needs Trust is discretionary, a trustee is not legally obligated to follow a Letter of Intent. The Letter of Intent nevertheless helps the trustee understand your relative's needs. Some parents start the Trust fund 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 interdisciplinary team (your son or daughter, family members if any, residential and vocational providers, Coordinator of Community Services, other advocate) 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) On average, one in three residential staff change every year, so eventually those working with your relative may be unaware of the trust.
- ii) The vast majority of people in services do not have a Trust, so teams are accustomed to planning without financial resources.
- iii) Team members may not understand the purpose of a Special Needs Trust or how to access funds. Or they may consider money a private matter and await a trustee to inquire about needs.

Possible strategies:

- (1) Provide your Letter of Intent to the residential agency or advocate about the purpose of the Trust and how to request funds. The State does not currently consider a Trust fund when providing services but that could change, so some families have provided this information only to a private advocate.
- (2) Provide a sample letter to your trustee to periodically send to the residential agency to inquire about your relative's current financial needs. <http://bytheirsid.org/resources-educational.html>
- (3) Involve a private advocate to visit, monitor, advocate, and provide updates including financial needs to a trustee or distant sibling. www.bytheirsid.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 eligible persons with an intellectual/developmental disability in urgent need. Apply for DDA services now so you have time to locate necessary documents and respond with additional information if needed, and so your relative will be on the DDA Waiting List when services are needed. <http://dda.dhmf.maryland.gov/SitePages/howtoapply.aspx>

Once on the DDA Waiting List, contact your Coordinator of Community Services if your situation changes and your need for services is becoming urgent. Funding for DDA services is reserved for individuals in urgent need, such as risk to health or safety including change in caregiver ability to continue care for health reasons or inability to manage individual behavior, etc. Keep a list of examples and any available 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 their websites to identify several that offer the type of services needed and whose beliefs about service provision match your own. Licensure records and investigations at the Office of Healthcare Quality are public record. While many providers are unable to schedule interviews until DDA has authorized funding, they may 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 as much as possible, including home tours and interviews with potential housemates or new staff. The Arc of Frederick County developed a comprehensive list of interview questions to be tailored to your needs. <http://arcfc.org/resources/factsheets.html>

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 identify other newly funded individuals seeking similar housing, who might like to consider being housemates.

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 if needed. 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 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 situation is often considered urgent by DDA and they may 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 or vocational programs will not transfer. Application could be made for similar services in the new state; most states have long waiting lists.

E.) Develop a written emergency plan – Who will assist in an emergency should something happen to you? Who can care for your relative for a day or two? Include DDA contact information in case long term arrangements are needed. Provide a copy of your plan to your emergency contact, close friend or neighbor and/or post it on the refrigerator where it can easily be found. The **Grab and Go Emergency Folder** helps organize important information to assure your relative's comfort and continuity of care. <http://arcfc.org/resources/emergency-preparedness.html> **If I Need Help** helps parents prepare information in a scan format that could stay with your relative e.g. ID card, clothing badge, shoe lace tab. [Ifinedhelp.org](http://ifinedhelp.org)

STEP 3. Prepare a sibling, relative, or friend as next generation advocate.

Some siblings report feeling inadequately prepared, or 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 Individual Plan meetings, after you are gone. Explore reservations and line up resources to assist. For example, if a sibling is not prepared to handle finances, let them know the residential agency can serve as representative payee or you will find another trustee.
- B. For a larger family, consider how your current 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 or if significant medical needs, attendance at key doctor appointments, so you can demonstrate how to work with the team and explain the process.
- D. Create an organized filing system for important documents. Help the next advocate pick up where you left off by keeping contact notes about issues, action, and resolution. A Personal Information Notebook Index is available at <http://www.bytheirsideside.org/resources-educational.html>
- E. You may wish to retain a private advocate to serve as an ally for siblings, especially those whose work may take them out of Maryland. www.bytheirsideside.org

STEP 4. Develop a written narrative to prepare current and future caregivers to respond to your relative's preferences and needs.

A transition to a new home, with a new routine, housemates, and caregivers, may be challenging for your son or daughter. The more information you can give the new residential provider about your relative, the better. Write down information while your relative is still home with you so it is available in the future, even if you can't be there yourself. This will also be valuable as 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?

Completing an individual profile can help assure your relative will continue to benefit from your knowledge and strategies learned over time.

<http://www.bytheirsideside.org/PDFs/Individual%20Profile%20Handwritten.pdf>

Contact information will be needed, such as

- Family emergency contact, now and 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 By Their Side's Personal Information Notebook Index for expanded list.

<http://www.bytheirsideside.org/resources-educational.html>

STEP 5. Plan 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 you may discuss religious beliefs about where they may be now. Residential staff, advocates, and others will be best prepared to support your relative upon your passing if you have prepared 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 advocate. In the future when you are gone, your relative may be comforted by continued visits with someone else they know.

Grieving resources are included in **Planning for the Future of an Only Child (and Those with Siblings)**, <http://www.bytheirside.org/images/PDFs/Futureplnguide.pdf>

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

Your son or daughter may enjoy seeing photographs or hearing their favorite family stories after you are gone. Creating a photo album or memory book together, or preparing one for him or her, 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, helps residential staff and visiting advocates to talk with your son or daughter about their past as well as gain insight into experiences and activities they may wish to enjoy again.

This document is available online for easy linkage to resources.
<http://www.bytheirside.org/images/PDFs/NextSteps.pdf>

*“The depth of the love of parents for their children cannot be measured.
It is like no other relationship. It exceeds concern for life itself.”
James E. Faust*

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Families asked By Their Side for assistance with planning for the future of an only child, including what to do after a Special Needs Trust is established. We wish to thank the dedicated members of the parent and professional focus group that met to explore these issues and related resources.

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