



Planning for the Future of an Only Child (And Those with Siblings)

As requested by families, By Their Side formed a parent and multi-disciplinary focus group to consider the issues and needs faced by families planning for the future of an only child. Through a series of meetings, the group explored the issues, then set about to identify resources and information. Many of the identified planning needs and questions are shared by larger families. **The issues center around understanding the future planning process, finding the right living situation, advocacy assistance and support through life transitions, estate planning and finances, decision making, quality of life, loss and grieving, and ongoing education and networking for parents.**

We wish to thank the dedicated members of the focus group:

Janet Ciesielski (Parent, By Their Side Sponsor)
Winnie and Phil Levinson (Parents, By Their Side Board)
Tracy Wright (Only child, By Their Side Board)
Judy Volkman (Parent, By Their Side Board)
Ron Christian (Arc Baltimore, Assistant Executive Director of Community Living)
Anjela McNally (Parent, Arc of Frederick County, Support Coordinator for Estates and Trusts)
Jean Doyle (Arc of Frederick County, Support Coordinator for Estates and Trusts)
Teresa Hall (Parent, Service Coordination Program Manager)
Eric Cole (Parent, Maryland Developmental Disabilities Council Chairperson, Dandy Walker Alliance President)
Andrea Toney (Parent, ADDPAC)
Michelle Bruns (Baltimore County Department of Aging, Caregiver Program Manager)
Kathy Vecchioni (By Their Side Executive Director)

This guide can be accessed online for easy linkage to resources.

<http://www.bytheirsidē.org/images/PDFs/Futureplnguide.pdf>

Issue 1: Understanding the future planning process

- **Planning Now.** (Rev 2012). Maryland Developmental Disabilities Council
A wide ranging overview featuring Maryland law, planning checklist, and more.
http://www.md-council.org/wp-content/uploads/2014/03/PlannGuide-v10_FINAL.pdf
- **The Arc's Center for Future Planning.** Information and resources, individual and family stories of planning, and archived webinars on useful topics. <https://futureplanning.thearc.org/>
- **Next Steps to Consider after Setting up a Special Needs Trust** A range of topics to continue the future planning process. <http://www.bytheirsidē.org/images/PDFs/NextSteps.pdf>
- **A Family Handbook on Future Planning** (2003), Sharon Davis, Ph.D. Editor, The Arc of the US. This handbook covers a range of future planning topics.
http://www.wrightslaw.com/info/future_planning_arc.pdf

- **Planning for Life**, Maryland Developmental Disabilities Administration brochure identifying State agencies that may be of assistance.
[http://dda.dhmfh.maryland.gov/Documents/2016/Planning for Life - Updated 1-14-16.pdf](http://dda.dhmfh.maryland.gov/Documents/2016/Planning%20for%20Life%20-%20Updated%201-14-16.pdf)
- **Top 10 Things that Parents Need to Know** Timeframe for DDA and SSI applications by the Montgomery County Commission on Disabilities.
[http://dda.dhmfh.maryland.gov/Pages/Developments/2015/Top ten things parents need to know.pdf](http://dda.dhmfh.maryland.gov/Pages/Developments/2015/Top%20ten%20things%20parents%20need%20to%20know.pdf)
- **By Their Side's Future Planning Resources** <http://www.bytheirsideside.org/resources-educational.html>

Issue 2: Finding the right living situation for my relative

- **Accessing Maryland Developmental Disabilities Administration (DDA) Services.** Apply for DDA services before needed for a smoother transition when the time comes. A Coordinator of Community Services will provide a home interview and answer your questions. Call DDA at 844-253-8694 or access the online application. <http://dda.dhmfh.maryland.gov/Pages/eligibility.aspx>
- **Emergency Services** DDA can fund in home supports or residential services for eligible individuals facing urgent need due to health or safety risks, or when caregivers can no longer provide necessary care. Update your Coordinator of Community Services about changes in your situation, or call DDA at 844-253-8694 to have an urgent need evaluated.
- **Appeal of DDA Decision** If your relative's disability existed prior to age 21 and he or she was not approved (or approved for supports only and you know residential services will be needed when you can no longer be there), provide your Coordinator of Community Services additional information and examples of difficulties that arise if you are not there. [By Their Side.org](http://www.bytheirsideside.org) offers short term assistance and successfully assists families with informal appeals. A lawyer with experience with DDA can assist with a formal appeal.
- **Guide to DDA Services-** Includes an overview of the types of services funded.
[http://dda.dhmfh.maryland.gov/Pages/Developments/2015/Participant%20Guide%20to%20DDA%20Services \(4-18-2014\)%20FINAL.pdf](http://dda.dhmfh.maryland.gov/Pages/Developments/2015/Participant%20Guide%20to%20DDA%20Services%20(4-18-2014)%20FINAL.pdf)
- **DDA Service Providers** Select your region to view provider list and their services, mission, and application process. <http://dda.dhmfh.maryland.gov/Pages/providers.aspx>
- **Selecting a Provider** The Arc of Frederick County provides a list of questions to select from when preparing to interview providers to determine best match.
<http://arcfc.org/resources/factsheets.html>
- **Next Steps to Consider after Setting up a Special Needs Trust** discusses options such as continued use of the family home, transitioning to a new home, visits with potential roommates and information parents can prepare in advance to promote continuity of care.
<http://www.bytheirsideside.org/images/PDFs/NextSteps.pdf>

Issue 3. Advocacy Assistance and Support Through Life Transitions

- *Who will help my relative through life transitions (aging, loss of job, financial change, etc) and coordinate new support needed?*
- *If needed later, how will new services or a new home be identified and change handled?*
- *Who will ensure the person centered plan stays about the person?*
- *Who will help coordinate between day and residential programs if needed?*
- *How to assure relative will have a knowledgeable advocate/resource coordinator?*

Resources

- **Coordinator of Community Services** State funded advocacy service.
<http://dda.dhmh.maryland.gov/Pages/coordination%20of%20community%20services.aspx>
- **By Their Side, Inc.** Family funded non-profit providing advocacy, visits and monitoring at the frequency arranged by each family, starting now or in the future. Very experienced advocates. Formed in 1965 by parents concerned with who would advocate for the son or daughter with a disability when the parents were no longer able. 443-279-1234; www.bytheirsideside.org
- **Next Steps to Consider after Setting up a Special Needs Trust**, Reviews transition to residential services and information parents can prepared in advance to ease a transition and help agencies to provide continuity. <http://www.bytheirsideside.org/images/PDFs/NextSteps.pdf>
- **Grab & Go Emergency Folder**, Specify your plan for who will assist in an emergency, and important information to assure your relative's comfort and continuity of care, should you be hospitalized without warning. <http://arcfc.org/resources/emergency-preparedness.html>
- **If I Need Help** Allows important contact and medical information as well as information on how to comfort and support your relative, to be with your relative at all times (scan badge or label, shoe tag, card, bracelet) for use by medical professionals, EMTs, Police, and others. ifineedhelp.org
- **Transitions After DDA Services Begin:** If your relative receives DDA services and his or her needs change, the interdisciplinary team (your relative, family, coordinator of community services, day and residential service representative, and others) can meet to discuss needs and preferences, and adjust the Individual Plan. Additional DDA funds can be requested. Individuals and families can also transfer DDA funds to a different day or residential program, or Coordinator of Community Services provider.
- **Retirement:** As your relative ages, he or she may no longer wish to participate in their current day activities. The interdisciplinary team can meet to discuss your relative's preferences and options. One option is to request transfer of DDA funding from a day program to residential services for a day tailored to your relative's needs and interests, such as sleeping later in the morning, attending a senior citizen's center some days a week, going on community outings other days.
- **Aging in Place:** If your relative receives DDA residential services and requires greater daily assistance and monitoring to assure health and safety due to aging, medical, or other factors, their interdisciplinary team can meet to update the plan. Changes may include requesting DDA funding of awake overnight supervision or 1:1 staff, for example. Some agencies have provided in-home hospice when needed.

- **Healthcare Companion:** Medical Assistance helps pay for residential services for people enrolled in a Waiver program. Medical Assistance will not pay for residential staff to stay with your relative on the same day it pays for your relative's inpatient stay at a hospital or rehabilitation facility. If your relative would benefit from a companion if hospitalized, the hospital can be asked to provide a "sitter". In home health organizations can also provide a sitter, for a fee. Additional DDA funds can be authorized in some circumstances if requested, or if available, a Special Needs Trust or ABLE account could pay for the service.
- **Senior Information and Assistance** assists aging caregivers and those supporting aging individuals with I/DD to identify resources. Call 1-800-243-3425 or visit the website for your local office <http://msa.maryland.gov/msa/mdmanual/10da/html/dasr.html>
- **Center Connection** is available in some areas of Maryland. While people attending senior centers need to be independent in activities of daily living, this service offers support such as reminders, encouragement to participate, help with a lunch tray, guidance through the day, and county transportation arrangements. Check with your local senior center.

Issue 4: Estate Planning and Finances

- *How much money is needed for a Trust? What can be left in a Trust eg house?*
- *Who will serve as a Trustee if we have no other family?*
- *How can we make our wishes known? How often should a Letter of Intent be updated?*
- *Who will manage benefits and serve as representative payee?*
- *How will the Trustee learn about my relative's financial needs and preferences?*

Resources

- The Future Planning resources listed above address estate planning.
- **Estate Planning Resources; Letter of Intent Template** The Arc of Frederick County offers an overview; comprehensive downloadable Letter of Intent template to guide use of the Special Needs Trust; and guide to choosing an attorney with a list of many Maryland attorneys specializing in Special Need Trusts. [http://arcfc.org/what we do/future-planning.html](http://arcfc.org/what_we_do/future-planning.html)
- **FAQs About Special Needs Trusts-** by Louise Michaux Gonzales, Esq, (updated 2014.) A Special Needs Trust enables your relative to benefit from funds you leave without reducing benefits. An overview of the Special Needs Trust, commonly asked questions, and distinctions between third party, first party, and payback Trusts. <http://www.bytheirsideside.org/PDFs/Trustfaqs.pdf>
- **Pooled Special Needs Trusts-** A Pooled Trust allows even a relatively small fund to be established as a Special Needs Trust. Funds are managed together but tracked separately, and include Trustee services, for a fee. Serving Maryland: The Arc of Northern Virginia Trust www.thearcfnovatrust.org and the First Maryland Disability Trust www.firstmdtrust.org.
- **Trustees-** Some fund managers, attorneys, and banks are willing to serve as Trustee.
- **ABLE Accounts-** The Achieving a Better Life Experience Act allows individual savings accounts for disability related expenses while protecting benefits. Implementation plans are expected around October of 2017.

- **By Their Side** Communication of individual needs to sibling advocates and trustees is a prime reason for involving By Their Side. Your relative's advocate is guided by his or her interests and needs as well as parent advocacy concerns. Advocates encourage plans to address needs and life enrichment opportunities, including facilitating requests for Trust funds when available. 443-279-1234; www.bytheirside.org
- **Administering a Special Needs Trust: A Handbook for Trustees**, Special Needs Alliance (2015 Edition) <http://www.specialneedsalliance.org/free-trustee-handbook/>
- **Managing a Home in Trust.** Leaving the family home in a Special Needs Trust for use in conjunction with DDA funded services enables your relative to benefit from established natural supports and community connections. Housemates supported by the same residential agency can pay rent to the Trust to support home maintenance. Arc Baltimore is one agency with experience supporting people in homes left in Trust. www.thearcbaltimore.org
- **What's Next? Steps to Consider after Setting up a Special Needs Trust** (2015) <http://www.bytheirside.org/images/PDFs/NextSteps.pdf>
- **Representative Payee** DDA funded residential agencies offer to serve as representative payee of benefits for the people they serve, for a fee. They issue personal use funds and should facilitate spenddown when needed to assure benefits are not jeopardized. Residential staff provide receipts for purchases to the agency's financial office. Financial Statements can be requested by family or advocates.
- **Social Security: Understanding SSI** Booklet www.ssa.gov/ssi
SSI Spotlights answer questions on topics such as: What amount can be set aside for burial expenses without effecting benefits? What income exclusions are allowed for impairment related work expenses? www.ssa.gov/ssi/links-to-spotlights.htm

Issue 5. Decision Making

- *How will self-direction and personal decision making be supported?*
- *How will health needs be addressed if my relative is unable to consent?*
- *Who will make the decisions that the parents would have made?*
- *How will decisions be made if there is no guardian?*
- *Is it important to formalize surrogate decision makers? If so, when? (eg healthcare surrogacy, advance directive, power of attorney, financial, representative payee, others)*
- *Guardianship: Options, benefits of having/not having a guardian*
- *If a guardian is desired, how do we identify someone?*

Resources

- **Supported Decision Making.** The United States endorses the United Nations Convention on the Rights of Persons with Disabilities. Article 12, Equal Recognition before the Law, requires support for people with I/DD to exercise their legal rights and safeguards to assure each individual's rights, will, and preferences are respected. In Maryland, families, interdisciplinary

teams and advocates work together to support people in services to make informed decisions to the greatest extent possible.

- **National Resource Center for Supported Decision Making** Resource library, stories of supported decision making, and more. <http://supporteddecisionmaking.org/>
- **Self Advocacy Groups**
People on the Go Maryland Statewide group that helps people with disabilities working to build confidence, skills, knowledge, and a sense of community. <http://www.peopleonthegomaryland.com>
Local Maryland Self Advocacy Groups <http://www.bytheirsides.org/resources-links.html>
- **Guardianship and Its Alternatives: A Handbook on Maryland Law** (Revised 2011) Most people with I/DD in Maryland services do not have a guardian; learn about options and safeguards. <http://www.aging.maryland.gov/egov/Documents/GuardianshipHandbookRev2011.pdf>
- **The Maryland Health Care Decisions Act's Surrogate Decision Making Law** Two health care professionals can certify a person to be unable to give informed consent for a specific medical procedure. This Statute allows a family member to sign for the procedure (in order of spouse, parent, sibling, other relative, and then close friend who knows a person well.) <https://www.oag.state.md.us/Healthpol/HCDASummary.pdf>
- **The Maryland Advance Directive** allows for the designation of a Healthcare Agent and Living Will <https://www.oag.state.md.us/healthpol/adirective.pdf>
- **Informed Consent for Medical and Psychiatric Decisions: What You Need to Know** (2005) This guide presents a framework for working with healthcare professionals to explore ways to support individual decision making and legal options for timely medical care. Contact info@bytheirsides.org or 443-279-1234 for a free copy, courtesy of The Arc of Frederick County.
- **"Five Wishes. Aging with Dignity."** In preparation for the event of being unable to make informed healthcare decisions, this legal document records a person's wishes about who should make their healthcare decisions, the kind of medical treatment desired, how comfortable he/she would like to be made, what he/she wants loved ones to know. (888) 594-7437 <http://www.agingwithdignity.org>

Issue 6. Quality of Life

- *Who will know my relative well, remember birthdays, etc.*
- *Who will assist to develop/maintain relationships, explore leisure/retirement options*
- *Who will assure meaningful work reflecting interests and strengths, and adequate wages*
- *Who will assure a continued good match with agencies providing services*

Resources

- An **Individual Plan** is updated annually for people in DDA services, and should include plans to address individual preferences, dreams, and needs, including goals worked on by residential and vocational staff to help with social networking, community participation and employment, as desired. The Coordinator of Community Services or other advocate should assure the IP promotes quality of life.

- **Coordinator of Community Services** State funded advocacy service.
<http://dda.dhmh.maryland.gov/Pages/coordination%20of%20community%20services.aspx>
- **By Their Side, Inc.** By Their Side is a family-funded, non-profit organization providing visits and monitoring with follow up, and advocacy in meetings, at the frequency arranged by each family, beginning now or in the future. Advocates carry forward information provided by parents such as preferred activities, friendships, traditions, support styles and hopes for the future. They work to assure individual preferences, needs, and family advocacy concerns are addressed, serve as a liaison with siblings and Trustees, and provide update reports to families or trustees.
www.bytheirsideside.org
- **Next Steps to Consider after Setting up a Special Needs Trust** Suggests information that can be prepared in advance by parents to ease a transition and help agencies to provide continuity, as well as preparing a sibling or private advocacy resource.
<http://www.bytheirsideside.org/images/PDFs/NextSteps.pdf>

Issue 7. Loss and Grieving

- *Support when friends, relatives, and ultimately parents die*
- *Support when staff change (1 in 3 staff leave each year on average)*

Resources

- **“Supporting people with learning disabilities through a time of bereavement and loss”** suggests a role such as greeting guests and offering refreshments, when a close family member is in home hospice, and support to 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 the person, using pictures to address facts, beliefs, and emotions to help cope with a life change through repeated readings as desired and discussion. Online resources help tailor a social story to an individual situation.
<http://www.pathfindersforautism.org/docs/social-story-about-death.pdf>
- **“Mental Retardation and Grief Following a Death Loss”** by Charlene Luchterhand, published by the Arc, January 1998. A handbook to prepare for the loss of a loved one and the grief that follows. Discusses ways to explain death, expression of grief, and steps to teach about death.
<https://www.dhs.state.il.us/OneNetLibrary/4/documents/DSP/GriefFollowingADeathLossTheArc.pdf>
- **Next Steps to Consider after Setting Up a Special Needs Trust.** Suggestions for helping others support your relative when grieving your loss, including preparing written instructions and involving an additional visitor beforehand if your son or daughter awaits your weekly visit.
<http://www.bytheirsideside.org/images/PDFs/NextSteps.pdf>
- **Aging and Disability**, L’Arche Canada. Ideas for supporting one another through the grieving process; emphasis on grieving in the context of a community of ‘differently-abled’ individuals. Includes L’Arche’s “Grief Support Kit” for facilitating groups with people with an intellectual disability. <http://www.aging-and-disability.org/en/grieving>

- **Resources in Coping with Grief, Death and Dying** Elizabeth Boggs Center and Robert Woods Johnson Foundation, 2009
<http://rwjms.rutgers.edu/boggscenter/projects/documents/EndofLifeResources3pp.july09.pdf>
- **Tips and Resources for Helping People with Intellectual Disabilities Cope with Loss** The Vanderbilt Kennedy Center for Excellence in Developmental Disabilities.
http://kc.vanderbilt.edu/kennedy_files/CopingWithLossandIntellectualDisabilitiesJune2011.pdf
- **“When Persons with Intellectual Disabilities Grieve”** Tips from the Equal Access Ministry.
http://www.ncpd.org/sites/default/files/When%20persons%20with%20intellectual%20disabilities%20grieve%200410_0.pdf
- **“Individuals with intellectual disabilities: Struggling with Loss and Grief”** by Kenneth J. Doka, PhD. Hospice Foundation of America.
<http://www.ddhospicepalliativecare.org/forum/ciwid.pdf>

Issue 8. Staffing/Support Agency

- *How to assure staff development and mentoring so staff are*
 - *Able to tailor support provision in a way that works for my relative*
 - *adaptable and help through life changes, and*
 - *willing to try new things, not settle for status quo*
- *How to develop a partnership between parents and agency, so agency can learn what parent knows about support needs/style, and teach that to staff even through turnover, even after parents are gone*

Resources

- **The Arc of Frederick County Fact Sheets** cover a wide range of informative topics such as interview questions to consider when selecting a DDA funded provider, negotiating with a provider, handling a disagreement with a provider, community connections, etc.
<http://arcfc.org/resources/factsheets.html>
- **Staff Mentoring** – Parents can assist their relative to develop staff guidelines that highlight important information, preferences for support style and routine, and community activities and/or relationships to continue. Providing a short list will help retain focus on the most important points.
- **“Holding the 10,000 Details: Productive Relationships Between Parents of People with Disabilities and Service Workers”** by John O’Brien and Connie Lyle O’Brien (2001)
<http://thechp.syr.edu/wp-content/uploads/2013/10/HoldingDetails.pdf>

Issue 9. Ongoing Education and Networking for Parents

- *Ongoing opportunity to come together and learn-- about developmental changes coming, services and resources*

Resources

- Local Arcs, Arc Maryland, the Maryland Developmental Disabilities Council, By Their Side, and disability specific advocacy groups plan and/or advertise educational and networking opportunities. Sign up on mailing lists to learn about opportunities. Sign up for DDA mailing lists for updates and opportunities.