



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:

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Winnie and Phil Levinson (Parents, By Their Side Board)
Tracy Wright (Only child, By Their Side Board)
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Andrea Toney (Parent, ADDPAC)
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Kathy Vecchioni (By Their Side Executive Director)

This document is available at www.bytheirsidē.org for ease of linkage to resources.

Issue 1: Understanding the future planning process

- **Planning Now.** Maryland Developmental Disabilities Council
A wide ranging overview featuring Maryland law, planning checklist, and more. An update on ABLÉ account changes dated 2024 is available.
http://www.md-council.org/wp-content/uploads/2014/03/PlannGuide-v10_FINAL.pdf
- **The Arc's Center for Future Planning.** Featuring information and resources, individual and family stories of planning, and archived webinars on useful topics
www.futureplanning.thearc.org
- **Planning for Life,** Maryland Developmental Disabilities Administration brochure identifying State agencies that may be of assistance.
<http://dda.dhmf.maryland.gov/SitePages/Developments/October12/5191CareGiver5.pdf>

- **Next Steps to Consider after Setting up a Special Needs Trust** addresses a range of topics to continue the future planning process. www.bytheirsideside.org

Issue 2: Finding the right living situation for my relative

Accessing DDA Services. Apply for DDA services before you need them to assure you have time to gather necessary information, and to allow a smooth transition later. A Coordinator of Community Services will complete a home visit and answer your questions about services to help you plan for the future. Call 410-767-5600 or access the online application www.dda.dhmmh.maryland.gov

- **Maryland Developmental Disabilities Administration brochure** highlighting the process to apply for day, residential, and support services. <http://dda.dhmmh.maryland.gov/SitePages/Developments/2014/DDA%20Brochure.pdf>
- **Developmental Disabilities Administration Guide to Services** Also see DDA website sidebar for list of providers in each region and website links [http://dda.dhmmh.maryland.gov/SitePages/Developments/2014/Participant%20Guide%20to%20DDA%20Services_\(4-18-2014\)%20FINAL.pdf](http://dda.dhmmh.maryland.gov/SitePages/Developments/2014/Participant%20Guide%20to%20DDA%20Services_(4-18-2014)%20FINAL.pdf)
- **Interview Questions to Consider when Selecting a Provider** by The Arc of Frederick County. Once funding is authorized or a needed change is identified, this resource provides a list of questions to consider when interviewing providers to determine best match. <http://arcfc.org/resources/factsheets.html>
- **Next Steps to Consider after Setting up a Special Needs Trust** discusses options for continued use of the family home or transition to a new home including visits with potential roommates and information that can be prepared in advance by parents to ease a transition and help agencies provide continuity. www.bytheirsideside.org

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, 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

- **Accessing DDA Services in an Emergency** Significant health or safety factors involving your relative or you as caregiver can result in DDA approval of funding for in home supports or residential services. Update your Coordinator of Community Services about your need. Keep a list of examples to show the urgency of your situation and documentation such as medical reports.

- **For Aging Parents:** Contact your Coordinator of Community Services or DDA (410-767-5600) to request a visit to discuss your need for services. If you prefer your relative to remain with you, in home supports may be offered to help ease his or her transition into residential care when needed.
- **Grab & Go Emergency Folder**, adapted by The Arc of Frederick County. 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. [arcfc.org/file_download/7de9d8a3-1ad9-4ab1-a3b7-639b45f664dd](https://www.arcfc.org/file_download/7de9d8a3-1ad9-4ab1-a3b7-639b45f664dd)
- **Next Steps to Consider after Setting up a Special Needs Trust**, discusses transition to residential services and information parents can prepared in advance to ease a transition and help agencies to provide continuity. www.bytheirsideside.org
- **By Their Side, Inc.** Formed in 1965 by Maryland parents concerned with who would advocate for their sons and daughters after they were gone, By Their Side is a family funded, non-profit organization providing advocacy in meetings, visits and monitoring with follow up, at the frequency arranged by each family, now or in the future. Advocates 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
- **Transitions involving DDA Services:** If your relative's needs change, his or her planning team (your relative, family, coordinator of community services, day and residential service representative, and other advocates) should meet to learn preferences then plan for and locate needed services including requesting additional DDA funds if needed. For people enrolled in a Waiver program, the DDA is required to provide additional funding to address a documented need. If a different service provider is needed, the DDA funding allocated for the current provider can transfer to the newly selected provider. Your relative may also change Coordinator of Community Services provider agencies if needed.
- **Retirement:** As your relative ages, his or her pace of life may slow to the point that he or she no longer wishes to participate in current day activities. Options reflecting his or her preferences can be discussed in a planning meeting, including a request to DDA to approve a change in funding of day services to reflect a "meaningful day" tailored to a person'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 or other factors, a planning meeting can be held to discuss options. The plan may range from their current staff adjusting the support provided to requesting DDA fund additional staff support, up to awake overnight supervision or 1:1 staff to assure health and safety needs are met. Agencies are unable to provide higher levels of medical care, but some have offered home hospice to a resident, for example.
- **Healthcare Companion:** If your relative has Waiver funding through DDA, Medical Assistance helps pay for residential services. Medical Assistance will provide personal supports while in an acute care hospital or facility if the need for such services were outlined in the Personal Supports Plan developed annually by the individuals's team. Medicaid waiver funds will not provide personal supports or assistance while in a rehabilitation or sub-acute facility other than one licensed by the Developmental Disabilities Administration.

- **Maryland Access Point (MAP)**, through the Maryland Department of Aging, is a gateway to long term supports and services for the aging in Maryland. MAP provides information on Senior Centers, Waiver Programs for Aging, in home care, Durable Medical Equipment re-use and other options. 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, guiding through the day, and making County Ride transportation arrangements. Check with your local senior center.

Issue 4: Estate Planning and Finances

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

Resources

- The Future Planning resources listed in issue one also address estate planning.
- **Estate Planning Resources** by The Arc of Frederick County. Includes an overview, comprehensive downloadable Letter of Intent template to guide use of the Special Needs Trust as you have intended; guide to choosing an attorney and a list of many Maryland attorneys specializing in Special Need Trusts. http://arcfc.org/what_we_do/future-planning.html
- **Pooled Special Needs Trusts**- A Pooled Trust allows even a relatively small fund to be established in a Special Needs Trust. Funds are managed together but tracked separately. Pooled Trusts available to Maryland families include The Arc of Northern Virginia Trust www.thearcofnovatrust.org, the First Maryland Disability Trust www.firstmdtrust.org, and

others.

- **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 Personal Support services enables your relative to continue to live in their home and benefit from established natural supports and community connections. Housemates can pay rent to the Trust to support home maintenance. Arc Baltimore has experience supporting people in homes left in Trust. www.thearcbaltimore.org
- **What's Next? Steps to Consider after Setting up a Special Needs Trust** www.bytheirsideside.org
- **Representative Payee** A residential provider agency can serve as representative payee for benefits. They issue personal use funds each month for personal care needs and spending, assist

with savings for preferred purchases, and monitor use of funds to assure the person does not exceed resources that could jeopardize benefits. Receipts are tracked for items purchased and accounts audited periodically. Financial Statements can be provided to family or advocates. Additionally, provider agencies can administer ABLE accounts for those in their programs. ABLE accounts allow individuals to save for future personal needs as well as safeguarding Medicaid eligibility (eliminating excess personal use funds.)

- **Social Security: Understanding SSI** Booklet www.ssa.gov/ssi
SSI Spotlights answer questions on 30 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
- **ABLE Act** - Achieving a Better Life Experience Act, allows individual savings accounts for disability related expenses while protecting benefits.

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, planning teams and advocates work to support people in services to make informed decisions to the greatest extent possible. In 2022, Maryland passed a bill legally recognizing and authorizing the use of supported decision making as an alternative to guardianship for people with disabilities.
- **National Resource Center for Supported Decision Making** Resource library, stories of supported decision making, and more. <http://supporteddecisionmaking.org/>
- **People on the Go Maryland** Self advocacy group of people with disabilities working to build confidence, skills, knowledge, and a sense of community. Also, ask your local Arc about other self advocacy groups near you. <http://www.peopleonthegomaryland.com/>
- **Alternatives to Guardianship** Maryland Courts The Maryland Courts website has a video library explaining alternatives to guardianship including Advance Directives, Surrogate Decision Making, Assistance with Personal Needs, Powers of Attorney, Representative Payees, Banking Services, ABLE accounts, Trusts and specific transactions, Supported Decision Making, Mediation. www.courts.state.md.us/
- **The Maryland Health Care Decisions Act's Surrogate Decision Making Law.** A person may be certified by two health care professionals to be unable to give informed consent for a specific medical procedure. This Statute allows a family member sign for the procedure (in order of spouse, parent, sibling, other relative, then close friend who knows a person well.)
5 <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>
- **“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> <https://www.agingwithdignity.org/forms/5wishes.pdf>

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

- **A Person Centered Plan** is updated annually for anyone receiving DDA funding, 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 Person Centered Plan promotes quality of life.
- **Coordinator of Community Services** This State funded service should provide advocacy to address individual preferences and needs. Several providers are funded in each region, and a change in provider can be requested.
www.dda.dhmf.maryland.gov
- **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 if needed in addition to the state funded Coordinator of Community Services. www.bytheirsideside.org
- **Individual Profile Completed with Family** Families can assist their relative to document preferred activities and routines, friendships and traditions, support styles and hopes for the future, for use by advocates and team when parents are no longer able to advocate. Parents can supplement information with their insights for a comprehensive picture. www.bytheirsideside.org
- **By Their Side, Inc.** Formed in 1965 by Maryland parents concerned with who would advocate for their sons and daughters after they were gone, By Their Side is a family funded, non-profit organization providing advocacy in meetings, visits and monitoring with follow up, at the frequency arranged by each family, now or in the future. Advocates 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

Issue 7. Loss and Grieving

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

Resources

- **“Supporting people with learning disabilities through a time of bereavement and loss”** by Cristina Gangemi. Describes support provided to someone coping with the terminal illness of his mother, through his religious beliefs, having the role of offering guests tea when they came to visit his mother in home hospice, and meetings with a guide to ask questions, process feelings, and work on a scrapbook of memories. <http://www.rcpsych.ac.uk/pdf/CGangemiSupporting.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>
- **Social Story about Death**, published by Pathfinders for Autism. Social stories can be adapted using online resources. A man with autism was assisted by a social story to cope with the death of his aide. The story in pictures told of their friendship, his belief that she watches over him from heaven, tears showing his feelings of sadness, and ending with happy memories of the things they did together. He read the story daily while processing his grief, with support from his parents when needed. <http://www.pathfindersforautism.org/docs/social-story-about-death.pdf>
- **Next Steps to Consider after Setting Up a Special Needs Trust.** Suggestions for helping others support your relative when grieving your loss, including involving an additional visitor now if your son or daughter awaits your weekly visit. www.bytheirsideside.org
- **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 Wood 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

- **Staff Mentoring** – Parents can assist their relative to develop staff guidelines to highlight important information, preferences for support style and routine, and community activities and/or relationships to continue. You can also provide guidelines regarding how your relative’s disability impacts his or her life, needs, strategies, and other insights. Providing a short list will help retain focus on the most important topics.
- **“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>
- **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>

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, and disability specific advocacy groups plan and/or advertise educational and networking opportunities. Sign up for email or mailing lists to learn about opportunities.