

PLANNING NOW

The Maryland Developmental Disabilities Council encourages you to copy and share the information in *Planning Now: A Futures and Estate Planning Guide for Parents of Children and Adults with Developmental Disabilities*. We ask that you credit the Council.

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MARYLAND DEVELOPMENTAL DISABILITIES COUNCIL
300 W. LEXINGTON STREET, BOX 10 / BALTIMORE, MARYLAND 21201

410-333-3688 / 800-305-6441
711 OR 800-735-2258 (MD RELAY)
EMAIL: INFO@MD-COUNCIL.ORG
WWW.MD-COUNCIL.ORG

A Message from the Maryland Developmental Disabilities Council

Raising any child to adulthood is full of challenges. For parents of children with disabilities, concerns about their sons' and daughters' futures are magnified. Some people with developmental disabilities will have a high degree of independence and others will need one or more advocates looking out for their interests all of their lives. Many people with developmental disabilities need support with some areas of their lives.

It is often difficult for parents to envision the future of their children with disabilities. However, with adequate planning and the right combination of support from a network of family, friends, and the disability service system, your son or daughter can lead a productive, satisfying life. Failing to plan could leave your child in an emergency situation with your hard-earned money not being used the way you intended.

Families in greater numbers than ever before are interested in planning for their minor children or their adult children with disabilities: where they will live, how they will receive needed support, and how the costs will be covered. Comprehensive planning should begin now. Review your plan and change it as your child grows older and circumstances change. As your child gets older it is important to plan with him or her. There are many things families can do to envision a desired future and to take steps to realize their vision.

Having a vision for your child's future (and helping your child develop his or her own vision as he or she gets older) and planning for that future are very important regardless of the type and severity of your child's disability, the make up of your family, or the amount of money you may have to plan with. Some goals may only be accomplished with a certain amount of money, but other wishes can be realized in other ways.

By planning, you can better assure that your child's personal and financial future is what you — and your child — desire and need. Your planning will help maximize your child's independence and dignity and the control he has over his own life. Through this planning, you can picture the involvement of your friends, relatives and service providers and direct any resources you may want to help. And you can picture your child in a community of people, with friends, a job or other meaningful activities and with needs and wishes fulfilled. This can happen with families whose children have significant disabilities, as well as those whose children have milder disabilities.

Picking up this guide may have been your first step. *Planning Now: A Guide for Parents of Children and Adults with Developmental Disabilities* will help you along the way.

Jeff Rivers
Council Chairperson

Brian Cox
Executive Director

Overview of the Guide

Planning Now considers some basic questions:

- How can families assist their adult children now, or their minor children in the future when they enter adulthood, to live where and with whom they want with the support they need?
- How can parents, during their lifetimes, assist their adult children to access a typical life outside the family home?
- How can parents or other relatives plan to help their loved one with a disability upon their death?
- How can they assist their family member to rent or buy a home?
- How can they design, establish and afford necessary support?
- How can they avoid jeopardizing essential public medical and financial benefits (like Supplemental Security Income and Medicaid)?

Planning Now discusses the importance of planning; provides essential information, suggestions, and a framework for planning; and then explains various tools and resources to assist you. We also talk about the types of professionals who can help, and provide useful worksheets and additional resources in the appendix.

You can use this information to develop a plan for helping your child become more independent and grow into an adult lifestyle while you are alive. You can also use this guide to design a plan for your child that others implement after your death.

There are as many individual circumstances as there are families with a child who has a disability. All financial, legal and planning options should be considered in order to work toward the vision you, your family, and your child have for the future.

We encourage you to review this entire guide, and other resources provided in the appendices, as you begin your planning and choose the pieces that apply to your family. Contact information on all organizations and resources referred to in *Planning Now* can be found in *Appendix B*.

Good luck!

About this Guide

Planning Now is not a do-it-yourself guide. Rather it is intended to explain important issues and ideas for you to consider; provide a basic understanding of financial, legal and planning tools that may help you organize and develop your plan; and assist you to select and work effectively with planning professionals. This guide is not intended to take the place of appropriate professional assistance.

Planning Now was written for parents who have a son or daughter of any age with a disability. It will be useful, as well, for other family members, close friends, and professionals like service coordinators, financial planners, attorneys and others who help families plan.

The guide is intended to provide information and ideas that are useful to families, regardless of how many, or how few, assets they may have.

For readability, we use the word “your child” to refer to adults and minor children. We also occasionally use “he” and “she” interchangeably but are always referring to both boys and girls, and men and women.



All information is correct to the best of our knowledge as of April 1999. However, because government benefits, laws, regulations and programs change, we urge you to verify information when you begin planning.

This publication is designed to provide accurate information regarding the subject matter covered. It is provided with the understanding that the authors and publisher are not engaged in rendering legal, financial or other professional service. Some information may be specific to Maryland.

Families are strongly encouraged to consult with an attorney and other professionals who have knowledge and expertise in estate planning as it pertains to the particular needs of people with disabilities.

Acknowledgments

Planning Now would not have been possible without the contribution of time, talent and ideas of many people. Early on, Delegate Sandy Rosenberg, Lorraine Sheehan, Naznin Adams, Kathy Cooper, Marge Gold, Nancy Kirchner, Susan Tager, and David Tomlinson took time to help us consider pertinent issues and set our course for this guide.

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Our source for the Financial Planning section and related materials in the appendix was *Facts About Financial Planners* by the American Association of Retired Persons, with additional information from the Institute of Certified Financial Planners, the International Association for Financial Planning, and Merrill Lynch. We appreciate AARP's willingness to share its well-reasoned guidance and thank Liz Oates of Merrill Lynch for our discussions on this topic.

Other guides that served as sources of information and/or ideas are *A Family Handbook on Future Planning* by The Arc of the United States, the *Community Supported Living Series* by the Wisconsin D.D. Council, and *The Fair Housing Act: Opening Doors for People with Disabilities* by the Bazelon Center for Mental Health Law.

Research of publications and pertinent activities throughout the country helped us formulate our ideas for *Planning Now*. We thank Meg Grigal for gathering and synthesizing this information. We also acknowledge Ralph Moore's work on an Estate Planning guide written for the Council in the 1980s when little information existed and his valuable feedback on this guide.

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This publication could never have materialized from an early idea of a planning guide to this substantial work without the commitment and vision of Brian Cox. The Council is indebted to him for his long-standing work, energy, and expertise.

Finally, we thank the parents who, with sincere generosity, shared their personal stories with us, as this helped guide our work. This included Susan and Doug Holland, Jackie and Michael Golden, Kathy Cooper, Bill and Ann Buchanan, and countless others over the years.

Written and edited by:

Diann J. Churchill, Attorney-at-law
Towson, Maryland

Brian Cox
Mindy Morrell
Maryland Developmental
Disabilities Council

Table of Contents for PDF Document

	Page
Section 1: Introduction to Futures Planning and Estate Planning8
Section 2: Common Principles and Trends15
Section 3: Government Financial and Health Care Benefits20
Section 4: Decision-Making26
Section 5: Wills and Letters of Intent34
Section 6: Trusts41
Section 7: Other Planning Considerations49
Section 8: Financial Planning55
Section 9: Services in Maryland60
Section 10: Planning Checklist69

Appendices

Appendix A: Glossary74
Appendix B: State and National Resources77
Appendix C: Pertinent Internet Sites86
Appendix D: Other Reading90
Appendix E: Planning Questions94
Appendix F: Person-Centered Planning Techniques96
Appendix G: Applicable Laws97
Appendix H: How to Evaluate Your Supplemental Needs Trust101
Appendix I: Important Documents and Information103
Appendix J: Financial Statement worksheet.105
Appendix K: Income & Expenses (Cash Flow) worksheet107
Appendix L: Questions to Ask a Financial Planner109