

A Family Handbook on Future Planning

Sharon Davis, Ph.D., Editor

December 2003

The Arc of the United States

and

**Rehabilitation Research and Training Center on Aging
with Developmental Disabilities
Department of Disability and Human Development
College of Applied Health Sciences
University of Illinois at Chicago**



UIC University of Illinois
at Chicago

OVERVIEW OF HANDBOOK

A Family Handbook on Future Planning is a guide to help families develop a future plan for their sons or daughters with cognitive, intellectual or developmental disabilities that provides personal, financial and legal protections for these individuals after the parents either die or can no longer provide care or support.

A Family Handbook on Future Planning is not designed to be a “do-it-yourself” guide to will writing, trust development and other legal processes. Instead, it is designed to help families review and inventory the needs and strengths of their family member, determine what should be in a plan and then locate qualified professionals and resources to finalize the plan.

This publication is an update of *A Family Handbook on Future Planning* published by The Arc in 1991. It incorporates and updates additional information covered in *How to Provide for Their Future* which was published by The Arc in 1989 and is now out-of-print. This new version is intended for publication on the World Wide Web, as most of the resources it cites are found on the Web.

ACKNOWLEDGEMENTS

The Arc thanks several individuals for their time and effort in reviewing the draft of this handbook. These include:

Rick Berkobien, Committee Administrator, Oregon State Legislature, former staff member of The Arc and original author of *A Family Handbook on Future Planning*.

Theresa Varnet, attorney for Spain, Spain & Varnet P.C., Chicago, Illinois and Northborough, Massachusetts, and active volunteer for The Arc.

Daniel Scarborough, Project Director, The Arc Aging Family Caregiver Support Project.

Alan Factor, Ph.D., Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago.

Steven M. Eidelman, Executive Director, The Arc of the United States

<p>This is a publication of The Arc of the United States and the Rehabilitation Research and Training Center (RRTC) on Aging with Developmental Disabilities funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research, under grant number H133B980046. The opinions in this publication are those of the grantee and do not necessarily reflect those of the U.S. Department of Education.</p>

A Family Handbook on Future Planning

Table of Contents

Chapter 1: An Overview of Planning	1
Considerations for Planning in Infancy and Childhood	2
Considerations for Planning in Adulthood	3
Planning for the Parent’s Senior Years	4
Questions to Answer in Developing a Future Plan	4
Personal Futures Planning	5
Planning Resources	6
Chapter 2: Financial Planning for Future Needs	7
Determining Your Son or Daughter’s Future Financial Needs	7
What Can the Family Provide to Meet Future Needs?.....	8
Arranging Future Financial Support for Your Son or Daughter	8
Financial Planning Resources.....	10
Chapter 3: Trusts	11
Types of Trusts Used for an Individual with a Disability	11
Setting Up a Trust.....	12
Laws Affecting a Trust	12
Funding the Trust	13
Trust Resources	14
Chapter 4: Guardianship and Alternatives to Guardianship	16
What is Guardianship?	16
The Need for Guardianship	17
Types of Guardianship	18
Alternatives to Legal Guardianship	19
The Steps in Legal Guardianship	22
Selection of a Prospective Guardian	22
Standards for a Good Guardian	23
Public and Corporate Guardianship	24
Guardianship Resources	25
Chapter 5: Preparing a Will	26
Need and Importance	26
Contents of the Will	26
Legal Requirements	27
Other Considerations Related to a Will	28
Letter of Intent	29
Letter of Last Instruction	31
Will Resources	32

Chapter 6: Government Benefits	33
Supplemental Security Income	33
Social Security Disability Insurance	33
Children and Disability Benefits	35
Medicaid	35
Medicare	36
Applying for Benefits	36
Resources on Government Benefits	37
Chapter 7: Preparing to Work with an Attorney	38
Selecting an Attorney	38
Attorney Fees	38
Evaluating Your Attorney	39
Revising Your Plan	39
Resources for Locating an Attorney	39
Attachments: Planning Checklist	40
Guardianship Position Statement	41
RRTCADD Resources	43

CHAPTER 1 AN OVERVIEW OF PLANNING

“What will happen after we’re gone?” is a question that parents of a son or daughter with a cognitive, intellectual or developmental disability are concerned about, particularly when the family member is still living with them. Parents may wonder where their son or daughter will live and how they will be supported in their daily lives, when they are no longer able to provide care. The concern increases as the parents age and may face declining health. Yet, many families fail to make plans for future living arrangements. They may also fail to make legal and financial plans that protect the son or daughter’s government benefits.

There are a number of reasons for failing to plan. In most states, there are long waiting lists for residential services. Families may assume that a brother or sister will take over the care of their sibling with a disability, even though they may not have discussed it with them. They may lack sufficient information about the many aspects of developing a future plan. Planning by older parents may be especially stressful as they confront their own mortality and the possibility that no one will provide their son or daughter with the same degree of love and support. When asked by The Arc why they did not develop a financial plan, families gave a number of reasons, such as: procrastination, attorney’s fees too high, not enough money to leave for the family member, lack of knowledge on how to plan and belief the government’s payment for services is sufficient.

Many families do recognize how important it is to plan for the future, so that their family member can be prepared for the transition to a new living situation before losing a parent when it becomes a crisis. This handbook is intended to guide families in developing legal and financial plans that will be implemented when the parent is no longer there to provide care. A future plan is different for every individual. However, there are some general rules to remember in developing a plan:

- Future planning involves more than just financial and legal planning. It focuses on all major areas of the person’s life such as living arrangements, educational programs, employment or other meaningful daily activities, leisure time activities and personal needs. Developing a letter of intent which is described in Chapter 5 is a useful tool for describing the array of services, supports and personal needs of the person with a disability.
- The individual with a disability should share in developing the plan. The plan should reflect what that person would like for his or her life. It may also be appropriate for siblings, personal friends and others who play a significant role in the person’s life to share in the planning.
- Future planning is an ongoing, dynamic process. The plan should be reviewed regularly to determine if it is still serving its intended purpose and revised appropriately as situations change.
- The plan must take into consideration the state in which the individual resides. Rules and statutes regarding services, legal issues and financial matters vary from state to state, and sometimes from county to county. Laws that affect planning also can change over time.

You should begin planning when your child is identified as having a disability and revise your plan as your child grows into adulthood. No one can predict when the plan will become active. A plan must be ready in case of a sudden death or other circumstances that would directly affect your son or daughter with a disability.

Considerations for Planning in Infancy and Childhood

The most important single need of all children, including a child with a disability, is for a guardian, decision-maker or advocate, which is the role normally played by parents. Some practical advice to parents for this first phase is:

Financial planning

- Be sure that your employment is covered by Social Security and that you are getting full credit for earned income whether you are self-employed or an employee of another. Social Security includes an extra benefit for dependents in case you become disabled, retire or die.
- Take optimum advantage of life insurance and disability insurance that may be available through your employment or through organizations you belong to, including The Arc of the United States. Your premature disability is more of a risk than your death while your child is a legal minor.
- Advise your parents, siblings and others not to give or bequeath any assets to your child with a disability, whether in trust or outright, without consulting you. Receiving an inheritance may have a negative impact on your child receiving important government benefits.
- If your child is unable to work due to a mental or physical impairment and has little or no income of his or her own, apply for Supplemental Security Income (SSI) to begin when he or she turns 18. (If your family meets income and asset requirements, your child under 18 may be eligible for SSI benefits. See Chapter 6.)

Planning for supports and independence

- Do whatever you can to enhance the prospects that your child can become more independent both economically and socially. Help him or her to move in the direction of self-support and self-direction as an adult, insist on a good school program and maintain positive expectations for him or her.
- Establish a social network for you and your child – the people that you can count on to help out, especially in an emergency. The most likely people are your neighbors, your extended family members, or members in your chapter of The Arc.
- If you have not already done so, join a local chapter of The Arc and become active. The Arc's ongoing advocacy is one of the resources your child will need 20 to 30 years from now. Your active support and participation today makes it more likely that it will be there when you are not.
- Begin to think about the time when your child will no longer be in school. Should he or she continue to live with you? What sort of work will he or she want to or be able to do? How independent or how much care or supervision will he or she need?

Legal planning

- Discuss with your spouse or other adult family members about possible strategies in the event you should die prematurely. Consider giving maximum flexibility to the survivor or another family member to make decisions based on future conditions. Discuss these plans with your attorney to ensure that your personal, legal and financial decisions all work together.
- Develop a joint will with your spouse that is designed for contingencies that might arise during the times your children are still minors. Remember to review and, if necessary, rewrite a will if and when circumstances change, especially as you approach your child's adult years when more detailed and mature planning can begin.

Considerations for Planning in Adulthood

The age of majority is 18 years old in most states. (It is important to know your state's laws as there are exceptions.) At this age, all people, including those with cognitive, intellectual and developmental disabilities, legally become adults. Adulthood brings with it legal rights and responsibilities. For example, an adult can legally enter a contract and be the decision-maker regarding medical treatment. Regardless of the severity of a person's disability, parents no longer have the legal right to decide for their family member with a disability. Parents may think that they can continue to sign legal documents and make other legally binding decisions for their adult child, just because that person has mental retardation. However, parents no longer have the legal right unless a court gives the parents that power.

Specific planning for your future as well as for the future of your now adult child becomes more urgent as you and your adult child become older. You should start talking in detail with your spouse and your children about what are often difficult topics: money and death. Areas to consider as part of a comprehensive plan include:

Financial planning

- Make sure you have adequate life and health insurance for yourself and your spouse.
- Estimate the extent to which your son or daughter may become partially or fully self-supporting, along with availability and cost of needed support services.
- Learn characteristics of your state's social service delivery system, income supports and Medicaid program for people with disabilities.
- Revise any revocable or time-limited trusts set up while your children were minors.
- Consider how to manage or dispose of your non-liquid assets, such as your house or other real property, especially if it has appreciated considerably.
- Consider the advantages and disadvantages of transferring some of your securities or savings gradually as gifts to your heirs, directly or in trust.

Legal planning

- Determine the need for a guardian for your child with a disability, or whether alternatives to guardianship can be used.
- Decide as to whether you will seek to be guardian of your adult child, at least for the time being, or ask someone else to become guardian.

- Recruit a successor guardian who you can name in your will to take over as guardian when you die.
- Review and update your wills when something happens that you did not anticipate – for example, if your offspring with a disability marries. In any case, review your will at least every five years.

Support planning

- Check with your local chapter of The Arc or other local developmental disability organization about the availability in your state of a nonprofit community trust or corporate guardianship or foundation concerned with ongoing life planning and advocacy for people with developmental disabilities.

Planning for the Parent’s Senior Years

As you age, you should prepare your son or daughter with a disability for the eventuality of your death. You may also wish to carry out some of the earlier made plans that involve other people. For example, if an older son is named as guardian in your will for his sister with a disability, you may now decide to ask him to assume that responsibility while you are still alive. Another option is to have him named as a co-guardian to avoid a gap in decision making should you suffer a sudden illness or die unexpectedly. The transition can be made smoothly and before any problems that could arise from your declining health.

Planning for your adult child with a disability should include a review of the person’s living situation, employment or other daily activities and leisure time. If he or she is still living with parents, when will this person transition to another living situation? It should also include retirement planning or personal assistance care for your adult child in the event a debilitating condition occurs.

Questions to Answer in Developing a Future Plan

A good plan is comprehensive. It covers a variety of areas and concerns parents may have about personal, legal and financial issues. Questions you may consider when developing a future plan may include:

Personal

- If still a minor, where and with whom would my child go to live if I am no longer able to provide care?
- Will my child become employed after completing school? Should I plan for a vocational training program?
- Where is my child going to be living in the future? Will he or she live alone, with a roommate or in a supported living situation?
- How should I plan for recreation, vacations, contact with other family members, medical services or necessary therapies?
- What other services and supports will my child with a disability need?

Legal protection

- Does my son or daughter have the judgment to make important decisions? If not, how can I be sure appropriate protective measures, legal or otherwise are in place?
- What is guardianship? How do temporary, limited, full guardianship, guardianship of the person and guardianship of the estate differ?
- Would guardianship meet my child's needs that cannot be met in other ways?
- What are the alternatives to guardianship?
- Why do I need a will? What is covered in a last will?
- What happens if I die without a will? What is meant by "intestate succession?"
- What is a letter of intent and how can it be used in planning?
- How do I find a good attorney if I don't already have one? Do I need an attorney who specializes in a particular area of law? How much will legal services cost? How can I tell if an attorney is doing a good job? Does the attorney have an ongoing role in the plan?

Financial security

- Can my child receive government benefits because of his or her disability?
- Is my child going to be able to work and earn a living wage? If not, how do I supplement his or her income? What amount is adequate?
- If my child is drawing a government benefit which restricts personal income and assets, how do I provide financial support that will not jeopardize this benefit?
- Who should I trust to oversee my child's financial care?

Personal Futures Planning

Some families engage in personal futures planning, a process for developing a plan with the individual with a disability. The planning process considers the whole person, including social, psychological and domestic lifestyle. It is a process that builds on the person's capabilities and strengths while designing a network of people and services to provide needed supports. The general steps followed in this process are:

1. Family or friends start by convening a team of people to discuss and outline a plan. The team includes the person for whom the plan is designed, family members, professionals and friends. The team meets periodically until a comprehensive plan is developed.
2. The team goes through a careful process of reviewing the individual's strengths, likes, dislikes and opportunities for growth. They look at the person's current and desired housing, education, employment, recreation, social networks, supports, community involvement and other important areas.
3. A plan emerges to build on and strengthen the person's life. It shows which people will be involved and by what means the plan will be carried out. The team develops a network of existing services, family, friends, natural supports and other traditional and innovative methods to ensure the individual has a plan to assist him or her in achieving a fulfilling life.

The following list of planning resources includes several sources of information on personal futures planning.

Planning Resources

Allen Shea & Associates. *A Resource List on Person Centered Planning*. Available on-line: <http://www.allenshea.com/resource.html>

Cornell University. *Person Centered Planning Education Site*. On-line course introducing popular person-centered planning tools at: <http://www.ilr.cornell.edu/ped/tsal/Enable/index.html>

Etmanski, A. (2000) *A Good Life for You and Your Relative with a Disability*. Available from: <http://www.agoodlife.org/>

Lutcherhand, C. (1998). *Mental Retardation and Grief Following a Death Loss, Information for Families and Other Caregivers*. A booklet to assist parents, friends, staff people and others who may some day be in a situation of consoling a person with mental retardation who has either just lost a parent or friend, or is near to someone whose death is imminent. Available at <http://www.thearc.org>; go to Resources and click on Publications and Videos. Find publication number 10-15.

Minnesota DD Council. *It's Never Too Early, Its Never Too Late, A Booklet About Personal Futures Planning*. Available on-line:

http://www.mncdd.org/extra/publications/Never_too_Early.PDF

Minnesota DD Council. *Making Futures Happen*. Workbook designed for facilitators of the personal futures planning process. Available on-line:

http://www.mncdd.org/extra/publications/Making_Futures_Happen.PDF

Smull, M.W. (1998). *Think Before You Plan*. <http://www.elpnet.net/beforeyouplan.html>

CHAPTER 2

FINANCIAL PLANNING FOR FUTURE NEEDS

Making financial arrangements for your son or daughter is an important part of planning. These arrangements help ensure a son or daughter is financially secure when you can no longer provide help. Making these arrangements can be complex because of the different factors that need to be considered. These include your own finances, your family member's needs and government benefits or other assets of the family member with a disability. It also includes your son or daughter's skills in managing money or other property.

There are four main steps in planning for the financial security for your child with mental retardation:

1. Determine your son or daughter's financial needs.
2. Identify and organize your assets.
3. Examine the factors that will affect how you distribute your estate or leave an inheritance.
4. Based on the information above, decide what to provide for your child with a disability and arrange the most appropriate method to make this provision.

Determining Your Son or Daughter's Future Financial Needs

Some people may have an easy time deciding how to distribute their estate. However, you, as parents of a son or daughter with a disability, will need to develop specific plans that take into consideration a variety of factors. Should you give your son with a disability a house so that he has a future place to live? If so, are there ways to be sure it is properly managed? Will a large inheritance to a daughter with a disability make her ineligible for publicly-funded disability services? Are your son or daughter's living expenses going to be greater than your other children's? Considering income and expenses, what share of the estate should your child with a disability receive? These are just some of the questions many parents have, and ones that deserve special consideration.

There are no standard methods or simple answers as to how you decide to provide for a son or daughter. One way to start is by estimating your son or daughter's living expenses, especially after you can no longer provide help and support. Then consider what resources your son or daughter has or will have in the future. Does your son or daughter have earnings from employment? Is he or she earning retirement benefits? Will he or she be eligible for Social Security benefits on reaching retirement age?

Is your son or daughter eligible for or receiving government benefits? Many individuals with mental retardation receive Supplemental Security Income (SSI), a monthly monetary allowance that makes the person eligible for Medicaid health benefits in many states. Adults are eligible for SSI if they have a disability which prevents them from working and they have limited assets (\$2,000 in 2003).

To help you determine the amount of money needed to provide lifelong financial support to your son or daughter with a disability, Merrill Lynch has a free financial calculator on their special needs web site (see Resources at end of chapter for web location).

Parents and others should not leave a direct inheritance, funds or property to the individual receiving SSI. If your son or daughter receives SSI and/or Medicaid and has access to more than \$2,000 in assets (e.g., from an inheritance), he or she would lose eligibility for SSI and Medicaid. The state might consider the inheritance an asset and he or she could incur "cost-of-care" charges, which means your child could lose Medicaid benefits, and would then have to use his or her own money to pay for services normally paid for by Medicaid. He or she would have to spend down the amount to below \$2,000 before reapplying for these benefits. Publicly funded residential costs, for example, can amount to several thousand dollars per month. Having to pay even some of these costs can quickly deplete funds that parents intended to supplement the individual's low personal care allowance. In some states, the state can bill for back cost-of-care if the individual lived at a state funded institution, even if they do not live there now. In this situation, the inheritance or gift will not have the intended benefit if the result is loss of benefits.

What Can the Family Provide to Meet Future Needs?

After estimating your son or daughter's needs, it is then time to review and organize your own resources. You start by identifying and listing your assets. Assets, your estate, are personal or real property to which you have title or in which you have legal ownership. Assets include, but are not limited to, such items as cash, homes, business interests, bonds, pension annuities, retirement accounts, other real estate, bank accounts, stocks, automobiles, life insurance, land and jewelry. Assets form the base of your financial plan. They are the resources you have at your disposal in arranging a secure financial future for your heirs.

You can dispose of your estate in many different ways. You need to decide how you want your assets distributed after you die. A good way to do this is by organizing assets into an asset inventory. Several web sites include asset inventory forms (listed at end of chapter). Information on your assets is important for your attorney in drafting your will. It will also be important if you should decide to develop a trust (discussed in Chapter Three) for your family member.

Arranging Future Financial Support for Your Son or Daughter

First, you need to assess whether or not your son or daughter who is disabled can adequately manage his/her financial affairs. If not, then determine the level of help he or she needs. Can he or she budget monthly income and pay bills in a timely manner? Is he or she prone to financial exploitation by others? If your child needs help, are other family members, friends or a support network available? Is your son or daughter receptive to receiving this type of help from others? There are no guarantees that your heirs, regardless of having or not having a disability, will wisely manage an inheritance. However, it is prudent to either educate your heirs about good management or have a mechanism in place to ensure good management.

Some of the ways you can leave money to a son or daughter with a disability in a manner that provides support are described here. These include informal arrangements, special accounts and trusts.

Informal arrangements

An informal arrangement does not involve a legal document that assigns and protects money or other property for a family member. Instead you leave money or property to a trusted relative or friend with an understanding that the asset is for your son or daughter's care. Not giving your child legal entitlement to these assets is also one way to preserve your child's eligibility for government benefits and avoid state cost-of-care charges. You may also use this type of arrangement with smaller estates of limited assets that do not justify the cost of certain legal protections.

The above approach is based on "moral obligation." It does not guarantee legal protection. Unfortunately, the assets intended to benefit the person with a disability may be at risk of not being spent on this person. For example, if you leave assets to a non-disabled sibling to use for your child with a disability, and the non-disabled sibling divorces or dies early, the extra funds may end up going to a divorced or widowed spouse or another heir.

Special accounts

You can set up a special account with a bank, credit union, investment firm or other financial institution. You could, for example, set up a joint account for your son who has mental retardation and your daughter who does not have a disability. This would enable your daughter to oversee the account. Purchasing a certificate of deposit for your son or daughter with mental retardation, making the person the recipient of an annuity or setting up investment plans in this person's name may also help ensure future financial support or assistance.

However, there are drawbacks to these methods. They do not normally guarantee the protection of a person's SSI benefit, especially if such an account places the recipient over the \$2,000 limit. Money in a joint two-signature general account is usually considered personal resources. The courts could tie up a two party account if one owner dies or divorces. This type of account also may be vulnerable to exploitation by others or mismanagement by the owners.

Many banks offer Totten trusts. This is a way to title an account so the balance automatically passes to a new owner when the person who opened it dies. For those not on SSI, use of these methods may provide some protection and stability of assets. However, they do not guarantee wise use or protections of such accounts against outside influence.

Trusts

A third approach is to set-up a trust. If necessary, certain trusts can protect a son or daughter's government benefits or avoid cost-of-care charges. In some states, parents with even modest resources can establish a trust in what is often called a "master cooperative trust" or "pooled trust." Trusts are described in the next chapter.

Financial Planning Resources

MetDESK (Division of Estate Planning for Special Kids) *Planning for Children with Special Needs*. MetDESK specialists are helping families plan for the future of their children with special needs. Information available on-line at:

<http://www.metlife.com/Applications/Corporate/WPS/CDA/PageGenerator/0,1674,P475,00.html>

Or go to www.thearc.org and click on MetDesk icon

Merrill Lynch. *The Families of Children with Disabilities Program*. Web site includes a financial calculator: <http://www.totalmerrill.com/TotalMerrill/pages/SpecialNeedsFinancialServices.aspx>

National Endowment for Financial Education (NEFE)

5299 DTC Boulevard, Suite 1300

Greenwood Village, CO 80111

(303) 741-6333

www.nefe.org

Available on-line from NEFE: *The Wealth Care Kit: A consumer guide to establishing and maintaining a financial wellness program*. <http://www.nefe.org/wealthcarekit/index.html>

Books published by NEFE for families with children with disabilities:

NEFE and Easter Seals. (2002). *With Open Arms: Embracing a bright financial future of you and your child with disabilities and other special needs*. (Easter Seals, 230 West Monroe St., Suite 1800, Chicago, IL 60606. 1-800-221-6827; 1-312-726-6200; www.easter-seals.org)

NEFE and PACER Center. (2001). *Possibilities: A financial resource book for parents of children with disabilities*. (Parent Advocacy Center for Educational Rights [PACER Center], 8161 Normandale Boulevard, Minneapolis, MN 55437. 1-888-248-0822; 1-952-838-9000; www.pacer.org)

CHAPTER 3 TRUSTS

Trusts hold money or property that the grantor, the person who sets up the trust, leaves for the benefit of another person, called a beneficiary. Unlike an outright gift or inheritance through a will, a trust usually contains carefully written instructions on when and how to use the trust's assets.

You or others can fund a trust while still alive or as part of a will. If you establish a trust while still alive, you can be the trustee (the person who manages the trust). You can also assign someone else to be trustee. A trustee can be a person, financial institution (bank), or in some cases, a not-for-profit pooled trust program. Laws regulating who may serve as trustee vary from state to state.

You may design a trust to distribute assets to one or more beneficiaries at certain times or under certain conditions. Some trusts make distributions to the beneficiary (or beneficiaries) over time. Others instruct the trustee to distribute just the trust's earnings (from interest or investments) or the amount the trustee thinks the beneficiary needs. Some trusts may require the accumulation of all income for distribution at a future time.

Types of Trusts Used for an Individual with a Disability

There are many different trusts for various purposes. Laws that affect trusts can also vary from state to state. However, most states have laws that authorize some form of supplemental, discretionary or even master "pooled" trust. Experts recommend specialized trusts when parents want to protect government benefits that their child needs. Some of these trusts are called "special needs" trusts. (The term "special needs" trust may have a specific legal and/or technical definition to state/federal agencies, attorneys or others.)

Supplemental discretionary trusts. Supplemental discretionary trusts are designed so that the principal (the amount put in the trust account) and its earnings (from interest or investments) supplement the beneficiary's basic care and do not replace the public funds required to pay for this basic care. This kind of trust is good for the SSI and Medicaid recipient whose assets cannot go above a specific level. The trust grantor can carefully direct that the trust not pay for services covered by Medicaid or other benefits received as a result of the child's disability. Instead, the trust would require the trustee to provide funds for certain items, services or other expenses not covered by SSI and Medicaid. Supplemental discretionary trusts can also be set up for someone who is not on SSI and Medicaid.

Discretionary Trusts. Some states allow the trust grantor to give the trustee full discretion in how much or how little of the trust to distribute. This kind of trust can also contain provisions that limit distributions so that the person remains eligible for government benefits. The trustee of a discretionary trust must be careful not to distribute money from the trust for goods and services or outright to the beneficiary in a way that will disqualify him from receiving or remaining eligible for publicly-funded services. There are several drawbacks to a discretionary trust. The trustee must be knowledgeable about the benefits a person is receiving

and how to report correctly on the distributions. The trustee has total power over all distributions and may hold back all or some of the trust's distributions. It is important that you choose a trustee whom you trust and who will take the time to learn how certain distributions from a discretionary trust will affect government benefits.

The difference between a supplemental discretionary trust and a discretionary trust is that the supplemental discretionary trust includes language that directs the trustee to use the trust funds to supplement government benefits and not supplant them. The discretionary trust simply states that all distributions are in the sole discretion of the trustee. The qualifying language regarding the grantor's intent to supplement government benefits is not included. Some states have required the trustee of a discretionary trust to pay for basic support when the grantor's intent to supplement government benefits has not been made clear.

Setting up a Trust

There are usually two ways to set up a legal trust with your attorney. It can be testamentary or inter vivos (living).

Testamentary. This means the trust is part of a will and does not take effect until after the person who drew up the will dies. Parents can change the trust's provisions any time the will is changed. If the intended beneficiary should die first, the will and trust can change. Tax-wise, this kind of trust does not require the person to file or pay income tax on it since there are no funds in it until after that person dies.

Inter vivos (or living). This means the person establishes a trust before dying. In doing so, the parents and/or others can make regular gifts to such a trust. Grandparents can make testamentary bequests from their will to the trust set up for their grandchild with a disability. Parents can be the trustee and manage the trust according to their own discretion. They can also assign someone else to be trustee to see how that person would manage the trust.

Laws Affecting Trusts

Third party trust is a general term for a trust that a parent or others (the "third party") establish for another person. Third party trusts are based on "common law," which means that trusts can be established by one person for another with certain conditions about how and when the trust is used (e.g., a special needs trust). Some states like New York and Illinois have specific state laws about special needs trusts. If established within certain parameters, third party trusts will not affect SSI or Medicaid eligibility.

The federal Omnibus Budget Reconciliation Act of 1993, called OBRA '93 for short, is a federal law that affects how people with disabilities can have a trust and still qualify for Medicaid. The Foster Care Independence Act of 1999, is a federal law that affects how people with disabilities can have a trust and still qualify for SSI. Both laws allow many people with disabilities to place their own money into a trust and become (or remain) eligible for Medicaid and SSI. These are referred to as OBRA trusts. There are limited ways that people with disabilities can place personal assets into an OBRA trust:

Individual “special needs” trust. The person with a disability must be under the age of 65, and the assets are his or her own assets (from an inheritance, personal injury suit, etc.). However, a parent, grandparent, court or legal guardian must establish the trust, and not the person with a disability. If any money is left in the trust after the person with a disability dies, it must then be used to pay back the state to cover the costs of publicly funded services that the person received over his or her lifetime. This is sometimes called a “payback” trust or “self-settled” trust. The Social Security Administration also refers to this type of trust as a “special needs” trust.

Pooled trust. The assets of a person with a disability are placed into a sub-account of a pooled trust program, which aggregates the sub-accounts for joint investment and management. Trust earnings are allocated to each individual’s sub-account according to its share of the pooled trust amount. The trust sub-account in the pooled trust program must be set up and managed by a not-for-profit organization. The trust is established for the individual by a parent, grandparent, court, legal guardian or by the individual himself. (For more information, see The Arc’s publication, *Pooled Trust Programs for People with Disabilities: A Guide for Families*, listed on page 15.)

Funding the Trust

Family’s assets. Many families plan on using their own assets to fund the trust. A special needs trust can contain personal property, such as artwork or the family home. Other assets include investments such as mutual funds and stock. You may also be able to name the trust as the beneficiary of your retirement plan.

Assistance and inheritance from friends and family members. You should ask grandparents and other relatives and friends to direct their gifts or bequests to your child’s special needs trust. Let them know that they could jeopardize your child’s benefits if they made direct gifts or bequests to your child.

Life insurance (The following discussion is taken from www.metlife.com, a product of MetDESK division of MetLife.). Many special needs trusts are funded, at least in part, with some type of life insurance. Life insurance provides an alternative that can create an asset. Insurance proceeds are generally paid free of income tax and, as long as the estate is not named as beneficiary, usually outside probate. It also can be free of federal estate tax when properly structured, and it allows you to provide the cash needed to provide for your child with special needs, while keeping the rest of your estate intact for your other family members.

Below are descriptions of the basic types of life insurance.

Term life insurance offers protection that insures your family for a specified period of time—usually anywhere from one to 20 years. A term policy pays a benefit if you die during the period covered by the policy. If you stop paying premiums, the insurance stops. These policies do not build a cash value.

Whole life insurance or permanent insurance provides protection, as well as a cash value. Additionally, many companies pay policyholders an annual dividend. Dividends provide both flexibility and increased value to your life insurance policy. They can add more coverage to your overall insurance benefits and can build a sizable cash value. They are not, however, guaranteed. Of course, life insurance should not be purchased solely for accumulation. Its primary purpose is protection.

Universal life insurance is flexible. These policies are interest-sensitive and permit the owner to adjust the death benefit and/or premium payments, within limits, to fit the individual's situation. Your premiums are credited to an accumulation fund, from which costs are deducted and to which interest is then credited. As with whole life insurance, the cash value is yours. You may withdraw it or borrow against it at any time. Read your policy carefully to understand how loans and withdrawals affect the death benefit.

Variable life insurance is for those who want to tie the cash value of their life insurance policy to the performance of the financial markets. You decide among several investment options how your net premiums are to be invested. While monies invested in the investment options have potential for growth, such funds are subject to market risks including the loss of principal. In other words, some may make or lose money depending upon the performance of the market and the investment options you select.

Survivorship life insurance is a joint insurance policy taken out on the lives of two people that provides death benefits on the second death when the money is needed the most. Since the policy premium pays one death benefit, the premium can be substantially less than separate stand-alone policies. There are many types of survivorship life insurance policies. Check with your attorney and insurance agent to determine the policy that will best meet your needs.

Your individual needs and the needs of your child will help determine which type is best for you. Insurance policies often contain limitations, exclusions, reductions of benefits and terms for keeping them in force. Be sure to ask for full details regarding the policy and its costs.

Trust Resources

Berkobien, R. and Varnet, T. (1999). *Future Planning: Making Financial Arrangements with a Trust*. The Arc of the United States. Available on-line: <http://www.thearc.org/faqs/trustqa.html>

Disabilities Law Project. (2003). *Estate Planning for Families of Persons with Disabilities*. Philadelphia, PA. Available on-line: http://www.dlp-pa.org/pubs/Estate_Planning_May_2003.pdf

Family Village. *Estate Planning & Special Needs Trusts*. <http://www.familyvillage.wisc.edu/general/estate.htm>

MetDESK (Division of Estate Planning for Special Kids) *Planning for Children with Special Needs*.

<http://www.metlife.com/Applications/Corporate/WPS/CDA/PageGenerator/0,1674,P475,00.html>

Or go to www.thearc.org and click on MetDESK icon

Met DESK, MetLife's Division of Estate Planning for Special Kids. *The Special Needs Trust*.

Available on-line: www.thearc.org/development/whitepaper3.doc

Ohio's Family Support Collaborative. *Special Needs Trusts*. Available on-line:

<http://www.state.oh.us/olrs/fsc/ASP/SpecialNeedsTrust.asp>

The Arc. (2002). *Pooled Trust Programs for People with Disabilities: A Guide for Families*.

Available at <http://www.thearc.org>; go to Resources and click on Publications and Videos. Find publication number 25178-ARC.

CHAPTER 4 PROTECTING INDIVIDUALS: GUARDIANSHIP AND ALTERNATIVES TO GUARDIANSHIP

The majority of people with mental retardation and related developmental disabilities can manage their own affairs with informal assistance and guidance from others, such as family and friends. If guardianship is necessary, it should be tailored to the person's needs. The appointment of a guardian is a serious matter because it limits a person's independence and rights. (See The Arc's position statement on guardianship at the end of this document, page 41.)

There is no magic formula to determine when or whether guardianship or limited guardianship is appropriate. An individual's abilities and needs must be the paramount consideration in deciding to seek guardianship or to find other less-restrictive approaches for legal assistance, protective service or problem-solving.

You should learn the guardianship and protective services laws in your state and consult with other parents, your chapter of The Arc and professionals in making this determination.

What is Guardianship?

Guardianship is a court-approved legal relationship between a competent adult (known as a guardian, limited guardian, conservator, etc.) and a minor or adult with a disability or other incapacitated person (known as a ward). It gives the guardian a defined degree of authority and duty to act on behalf of the ward in making decisions affecting the ward's life. Each state has its own specific laws on guardianship. There is no uniform national guardianship law. However, the following generally describes the guardianship laws throughout the United States:

Guardianship of a Minor Child

By state law, all parents have guardianship power over their own minor children. The guardianship law for minors does not distinguish between children with mental retardation and those without a disability. All children up to a certain age, usually eighteen years, are under their natural parents' guardianship.

Even in divorce, both parents remain the lawful, natural guardians of the children. However, in determining the child's custody, the court determines which parent has priority in exercising the legal authority of the natural guardian.

If one parent dies, the surviving parent continues as natural guardian. If both parents die before the child reaches legal adulthood, the court appoints a guardian to replace the natural guardian. The court appointed guardian will remain in this role until either a court removes the guardianship or the ward reaches the age of majority, whichever comes first.

In choosing a guardian for a child, most state laws instruct the court to follow a preferred list of people in the parent's will. Some parents do not have a will or did not list in a will the preferred guardians for their children. In these cases, the court will usually consider the state social services department or whomever is available, capable and willing to accept the

responsibility. Appointment also depends on the court finding the preferred person(s) qualified and approving the person(s) as guardian(s).

Guardianship of an Adult

Guardianship is a legal, not medical determination. When people with mental retardation and related developmental disabilities become adults, they have all the legal rights and responsibilities of any adult. A doctor, psychologist, social worker or attorney cannot assign legal guardianship over a person. Only the court can make one person the guardian of another person. The court's decision is usually based on the person's abilities to handle personal decisions, money, property and similar matters. The incapacity (or legal inability) to handle these matters is the grounds for a guardianship, not mental retardation or other disabilities.

The Need for Guardianship

Decision-making about the need for and extent of guardianship for an adult with mental retardation should not be made solely on the basis of psychological testing or the presence of mental retardation. Too often in the past, courts have removed all decision-making rights from an individual with mental retardation based simply on the fact of a diagnosis. Appointment of a guardian should be made only to the extent necessary for the protection and welfare of the individual, and based on the individual's abilities and needs. Guardianship should be established to ensure the person retains as much independence as possible, especially in areas in which he or she possesses capable decision-making skills.

There may be different reasons why an individual with mental retardation and related developmental disabilities may need a guardian. Some common reasons are:

- The person has assets he or she cannot adequately manage. Someone is needed to be sure the assets are secure and used for the intended purpose.
- The person needs medical care or other services that will not be provided unless there is a clear understanding about the person's legal capacity to consent to treatment or services. Health and service providers are becoming more concerned about liabilities when providing services to someone who may not have the capacity to make an informed consent to treatment or services.
- Parents or siblings cannot get access to important records or provide other help without guardianship. As a legal adult, a person with mental retardation must often give consent for the release of health and other records to parents or others. Health and service providers unsure of the person's ability to give consent may require documentation of the person's legal capacity before allowing access to records without the person's consent. (Note: The recent implementation of the federal law, the Health Insurance Portability and Accountability Act, or HIPPA, creates new and significant penalties for health care providers and others who release records without approved consent of the patient or client.)
- An individual with mental retardation may require an advocate's help, someone who has a legal status or relationship to that person.

For many parents, the need to petition the court for guardianship will be quite clear. For other parents, deciding on the need to petition the court for legal guardianship may be difficult.

To help with this decision, you should consider the guardianship laws in your state and the alternatives to guardianship.

Types of Guardianship

Types of guardianship vary depending on state law. State laws may differ in defining incapacity, interpreting the guardian's duties and qualifications, terminology, reporting, documentation, costs and other areas related to guardianship. In general, types of guardianship fall into several categories:

Guardian of the Person or Property

Guardianship is sometimes characterized as “guardian of the person” or “guardian of the estate.” In guardian of the person, the individual needs a guardian to decide personal issues. These decisions may include where to live, consent for medical treatment and signing for services.

The court will usually identify specific decision-making areas under guardianship of the person. Courts frequently require periodic reports from the guardian about the guardian's actions over the course of the year or other period.

A guardian of the estate, called a conservator in most states, usually has power just over the ward's money or property, not the individual's personal matters. Some states also do not require a judgment of the person's incapacity for a guardianship of the estate. The court can base the need for conservatorship just by finding the person unable to manage assets or property.

The court requires this type of guardian to protect the person's property and use it for the person's care, support, education and other areas of general welfare. The guardian of the estate must use the ward's money for the ward's care and account periodically to the court. Guardians who have foolishly invested or embezzled their ward's money may have to pay it back from the guardian's own money or face criminal charges for fraud. They must also keep good records and make them available to the court. Some states require this guardian to put up a bond.

Full Guardianship

A full or plenary guardianship basically includes guardianship over all the person's personal and property decision-making. It is usually a collection of all the powers and responsibilities mentioned above. Full guardianship is quite common, as it is the kind with which courts are most familiar.

Since full guardianship involves controlling every aspect of the person's life, it is the most restrictive. Full guardianship is useful for individuals whose mental retardation is so severe that they are not capable of making proper decisions. Before choosing full guardianship, alternatives, including limited guardianship, should be explored.

Limited Guardianship

Many states have designed laws for “limited guardianship” to encourage a person to keep as much control as possible over his or her own life. Under this legal approach, the guardian has authority over the ward only in specifically defined matters. Every decision outside of those defined areas remains with the individual who has mental retardation. This form of guardianship allows the legal guardian to decide only in areas where the person is not capable.

Limited guardianship does require more attention from the court, attorneys and guardians to ensure it is specific to the individual’s needs. The court, in considering limited guardianship, also must try to foresee all the individual’s future legal needs. For example, an unpredictable legal situation might arise that is not covered under the limited guardianship. The guardian may not have the authority to provide needed protection and may have to return to court to get more decision-making power.

Note: Guardianship does not always fall under just one or the other of the above categories. In many states, the court may authorize a mix of guardianships. For example, a person may need full guardianship of the estate and only limited guardianship over certain personal matters.

Temporary Guardianship

Some states allow guardianship for a limited time. If a legal problem arises from a specific situation, the court can issue a “protective order” or temporary guardianship. Under a protective order, the court can give another person, a public guardian or corporate guardianship program (these last two are discussed later) the legal authority to handle the specific situation. When the problem is resolved, the order ends with no permanent guardianship.

Temporary guardianship usually applies to temporary situations such as those caused by drugs, acute illness or special medical situations. It has limited uses for long-term, reoccurring medical situations or incapacities due to disability. This allows family members or an agency to obtain temporary guardianship if medical or other treatment is necessary, but not given due to the person’s questionable ability to consent. Once the person has treatment provided, the guardianship is removed.

Alternatives to Legal Guardianship

Before pursuing guardianship, parents should first consider using less intrusive, even non-legal, measures. For example, someone who lives alone and has trouble managing money may not need a legal guardian. Rather, the person may only need a restricted bank account and the occasional visit of a case manager, family member or other trusted person for help in budgeting money and paying bills.

Below are some methods or services that may provide the protections or supports a person may need now or in the future. These do not always carry the “legal weight” of guardianship. Instead, they (1) may only legally protect the person or property to a limited degree; or, (2) are non-legal services or options that may meet the individual’s needs instead of

legal guardianship. It is a good idea to consult with a knowledgeable attorney experienced in disability issues to make sure alternate plans do not inadvertently jeopardize government benefits or create other legal problems.

Representative Payee

Some individuals with disabilities receive government, military and other benefits. They usually receive these benefits by check made payable to the recipient. Many individuals with mental retardation can manage this money. However, others may not have good money management skills or are vulnerable to exploitation by others.

The administrator of these benefits, such as the Social Security Administration (SSA), may sometimes assign a representative payee for a recipient of these benefits. This payee receives and distributes the benefits when the individual with mental retardation cannot manage the check. In some cases, family members serve as Representative Payees. However, in many instances non-governmental organizations (i.e., public guardian offices, community mental health centers, clubhouses, or even for-profit companies) serve as Representative Payees. The payee must regularly account to the benefit's administration on the use of the benefit check, and is liable to repay money if it is mismanaged.

The decision to assign a representative payee to someone is usually based on non-legal documents such as a doctor's report. Contact your local SSA office or administration office of other benefits for more information on the representative payee system. You may also find information on SSA's web site: <http://www.ssa.gov/payee/>.

Joint Property Ownership

Families often worry about their son or daughter's skills in managing their own home. They may fear the property would be poorly maintained, lost due to a tax lien or sold against their wishes. These potential problems may be avoided by placing property in joint ownership under the names of the son or daughter with mental retardation and another trusted person. However, property worth more than a certain value, if not connected to the person's home, may jeopardize a person's SSI benefits. Joint ownership may also be subject to other potential problems. For example, if a non-disabled sibling who co-owns the property was to divorce, the spouse of that person could claim a portion of the co-owned property under a community property settlement. The jointly owned property could also be subject to creditors if that non-disabled sibling were to have financial problems.

Joint Bank Account

Most banks can assist with creating a bank account to help manage money. For example, benefit checks can be directly deposited and certain bills automatically paid. It may also be possible for spending money to be sent regularly to the individual from his or her account. A joint bank account can help an individual manage money and prevent excessive expenditures.

Trust Account

Setting up a trust, discussed earlier in this publication, may protect money or other property from being overspent or mismanaged. A carefully written, restricted trust may provide financial protections that relieve the need for other legal protections such as guardianship.

State Programs

Some states have laws that can protect the individual or the individual's property without having to rule the person incapacitated. A state may contract with a nonprofit advocacy and guardianship agency to provide trusteeships and protectorships for certain individuals with disabilities who may need assistance or protection. There are usually certain stipulations to using these types of services and not all states have laws that authorize these programs. Check with your chapter of The Arc or local mental retardation agency to determine if such laws are in effect in your state.

Living Will/Healthcare Directive and Durable Power of Attorney for Health Care

A living will or healthcare directive spells out the sort of medical treatment an individual wishes or does not wish to receive when the person is unable to communicate that information. A doctor who receives a properly signed and witnessed document is supposed to honor the instructions or transfer the patient to a doctor who will. Often used to specify the withholding of life prolonging treatments, a living will could indicate that the individual would like all the medical treatment that is available.

A durable power of attorney for healthcare is a legal document that gives another person (typically parents) authority to make medical decisions for the individual with mental retardation. Since the document does not necessarily state the type of medical treatment the individual prefers, the person with power of attorney has the authority to make medical decisions. However, if the individual also has a living will, the two documents should work together to ensure the person receives the desired type of treatment. Hospitals and senior centers often provide help with healthcare directives free of charge and have standard forms that can be used. You may also have your attorney handle this as part of your plan for your family member. The durable power of attorney for healthcare must be written and notarized. It may be helpful to have supporting documentation that the individual with mental retardation is competent to designate someone as power of attorney. Often this can take the place of a guardianship of the person. The document goes into effect once it is signed and can be terminated at any time by either of the parties.

Durable Power of Attorney for Property

This is a legal document in which a competent adult designates someone (referred to as the agent) to manage his or her financial affairs. There are benefits and drawbacks to this option, but it may be appropriate in certain circumstances. Benefits are that the individual with mental retardation remains competent in the eyes of the law and the court does not have to get involved by appointing a guardian of the estate or property which can be intrusive and costly. However, since the individual remains competent, he or she may enter contracts that may not be in his or her best interests. A "durable" power of attorney stays valid even if the individual becomes incapacitated.

To create a legally valid power of attorney, you need to complete a power of attorney form. Your attorney can prepare it, or you may obtain one from a bank or other source. After you fill out the form, your son or daughter must sign it in front of a notary public. Again, it may

be helpful to have supporting documentation that the individual with mental retardation is competent to designate an agent.

Durable Power of Attorney for Advocacy

In some states a power of attorney for legal advocacy can be created. It is a legal document signed by a competent adult who designates an agent to assist in making or voicing decisions. A form can be drafted that specifies what areas of assistance the individual may need. It can serve as a form of protection, allowing the agent to ensure that the individual understands and is capable of making decisions and providing consent. Like other power of attorneys, the individual remains competent but in need of assistance in making decisions. Parents may consider this option when their son or daughter reaches the age of majority and needs assistance in making decisions about his or her Individualized Education Program.

The Steps in Legal Guardianship

Each state has its own legal procedures or processes in determining the need for guardianship. The following steps are typical:

1. Someone – usually parents or other concerned people – file a petition with the court that has jurisdiction over the person whose competency is in question.
2. The petition is then delivered to that person.
3. The person petitioned for guardianship appears before a judge for a competency hearing. Most states require that the proposed ward physically appear at the hearing. If the person's medical condition prohibits a personal appearance in court, some judges will require a physician's letter, explaining why this person cannot appear in court.
4. The judge bases the decision to appoint a guardian on appropriate evidence. The amount and nature of this evidence may vary with each state. Some states may be willing to establish guardianship based on the family's testimony. Others may require evidence from someone who is outside the family. This can include physicians, psychologists, social workers or other appropriate professionals. In some states, the judge will appoint a representative or attorney to defend the legal rights of the prospective ward.
5. After hearing all the evidence, the judge will rule on whether the person is incapacitated and needs guardianship, and if so, establishes some form of guardianship.

Selection of a Prospective Guardian

It is usually advisable to name a successor (or sometimes called testamentary) guardian in your will. A successor guardian is just that, someone whom you wish to be guardian of your ward after you die or can no longer fulfill the role of guardian.

The person named as testamentary or successor guardian should be carefully selected and should agree to this responsibility. You may want to name your spouse initially. Subsequently, you will want to consider someone who is likely to outlive the ward because the guardianship may continue indefinitely. However, a court will have to ultimately authorize this person before he or she can legally take this role.

Because the designated guardian will have direct responsibility for making decisions about the ward's personal lifestyle, living arrangements, health care and other matters, he or she should not only be personally acquainted with the ward, but also should be a person who knows where to look for advice in selecting services. At the same time, the guardian should view himself or herself as an advocate for the ward and should be able to respect and interpret the ward's own preferences and wishes; these preferences should be balanced with what others might see as the ward's best interests.

You should consider making provisions to cover out-of-pocket expenses incurred by the guardian for travel, for professional consultation and for other activities. These can be covered from the ward's funds, from a trust or in some other way. A guardian's personal concern for a ward can't be bought; assistance with legal technicalities can be, and a guardian should have access to the advice of an attorney and the means to pay for that advice if necessary.

There are certain qualities and characteristics you should seek for the person who will be guardian. While this is not an exhaustive list, the person should:

- Live relatively close to the ward.
- Have enough time to assist this person and carry out the legal responsibilities.
- Be willing to learn about new programs for people with mental retardation and related developmental disabilities.
- Be willing to adapt to changing circumstances.
- Have good property management skills if he or she is guardian of the estate.

While it may be useful for you to prepare a "letter of intent" describing the personality and preferences of your child (see page 29), you should realize that both your child and the circumstances will change. You should place confidence and trust in the guardian to adjust to changing circumstances and not attempt to predetermine what decisions should be made. You should not, for example, try to make a life contract with a residential provider or lock in a specific living arrangement. It is your son or daughter's life, even if he or she will need ongoing guidance or supervision.

A situation may arise where a guardian is unavailable to perform guardianship duties. Some states now allow the guardian to assign the guardianship power to another person for a short period under a power of attorney. This provision of the law is only for genuine, temporary situations such as short-term illness or distant travel by the guardian. If the appointed guardian cannot perform the legal duties, then this person should resign and ask the court to appoint a successor guardian.

Standards for a Good Guardian

As a parent who becomes the guardian of a son or daughter with mental retardation, you are not likely to dramatically change how you interact with or relate to your new "ward." Even though you may have new responsibilities as a guardian, such as record-keeping and periodically reporting to the courts, your daily role with your adult child will likely continue as it did before the guardianship. However, the relationship between a guardian and a ward, the responsibilities

of being a guardian and the decision-making legally given to a guardian does merit further discussion and is an area that any guardian, including parent guardians, should consider.

In the early 1990s, the National Guardianship Association (NGA), a newly formed group of professional guardians, advocates and others adopted a code of ethics and standards of practices to help guide professionals and parents on issues that guardians face, and how to respond to these issues in the day-to-day role of guardian. These standards have been continually reviewed and updated, and today comprise 24 different standards covering areas such as informed consent, confidentiality, conflict of interest, self-determination, and other areas. While many of these standards may be more germane to professional guardians, you or other family members may want to review these standards, which may help provide guidance in undertaking the role of guardian.

You can read or download a copy of the NGA's Standards of Practice from their web site at: <http://www.guardianship.org/pdf/sofp.pdf>.

Public and Corporate Guardianship

There will not always be a parent, other family member or friend to act as guardian of a person with mental retardation. If family members or friends are available, they also may be unwilling, unavailable or not qualified to take this role. For these and other reasons, most states have appointed public guardians or have laws which allow corporate guardianship programs.

Public Guardianship

Some local and state government agencies provide guardianship to people with no family available or willing to become guardian. This is referred to as public guardianship. Nonprofit organizations under contract with the state or local government may also provide public guardianship services.

Public guardians often have large caseloads and time-consuming amounts of paperwork. Some public guardians may also have other duties, so must divide their time between responsibilities. These responsibilities can limit the time and resources public guardians have available to assist their wards. Thus, this type of guardianship is often considered as a last resort, especially for those who have financial resources, or can secure an individual guardian – or get the services they need elsewhere.

State resources generally finance public guardianship. Although states usually have safeguards which free public guardians to advocate for their wards, a conflict of interest could arise if a public guardian should have to oppose another state-funded agency. If public guardianship is being considered for a person with mental retardation, care should be taken to be sure these guardians have the time, resources and latitude to fulfill their responsibilities.

Corporate Guardianship

Many states allow incorporated agencies to provide guardianship and related services to people with mental retardation. In these agencies, the corporation is the guardian and assigns a professional staff person or volunteer to carry out the guardianship responsibilities. These

organizations often provide legal guardianship, individual service coordination, periodic support and even temporary guardianship. Parents can contract with such an agency to start specific services either after they die or when they can no longer help their child. Some state agencies also contract with these organizations for guardianship services. The organization's revenues may come from advanced funding from parents, bequests from the parents' estates, life insurance, United Way funding and contributions or subsidies from other organizations such as chapters of The Arc.

Before contracting with a corporate guardianship agency, you should investigate the organization to be sure it is well managed, has stable funding and provides quality services. There must be adequate proof the program will remain solvent and continue to supply good services throughout the lives of its wards.

Guardianship Resources

Berkobien, R. (1997). *Future Planning: Guardianship and People with Mental Retardation*. The Arc of the United States. Available on-line: <http://www.thearc.org/faqs/guard.html>

National Guardianship Association, 1604 Country Club Rd., Tucson, AZ 85716 (520-881-6561) <http://www.guardianship.org/> The mission of NGA is to establish and promote a nationally recognized standard of excellence in guardianship.

The National Academy of Elder Law Attorneys, 1604 Country Club Rd., Tucson, AZ 85716 (520-881-4005) <http://www.naela.org/> The National Academy of Elder Law Attorneys, Inc. is a non-profit association which assists lawyers, bar organizations and others who work with older clients and their families. Established in 1987, the Academy provides a resource of information, education, networking and assistance to those who must deal with the many specialized issues involved with legal services to the elderly and disabled.

CHAPTER 5 PREPARING A WILL

Need and Importance

A will is a legal document that is a concise statement of what you want to have happen after your death. While there are guides for drafting your own will, when you have a child with a disability, you should have an attorney prepare your will. The attorney translates your wishes into legal language that will assure their fulfillment within the limits of the law. A will should specify how property is to be distributed among your surviving spouse, children, other relatives, friends and charitable organizations or others. A will should be made in light of current conditions to protect your family in the event of sudden death. If you are competent, the will can be revoked, amended or changed at any time during your lifetime.

A will can provide for property distribution, for naming a guardian—subject to state court confirmation—or in some states a conservator or limited guardian, for creating a trust or for the purpose of transferring assets upon the death into a trust that already has been created.

Developing a proper estate plan, including a will, is necessary even though you and your spouse own all of your assets in joint tenancy (ownership or occupancy) with a right of survivorship, as community property or in other forms of mutual property ownership. Even if your assets are very limited and debts or liabilities may exceed them, a will can still be a useful document for expressing your desires and intents on what provisions should be made for your children. Such a personal expression could include the nomination of a testamentary guardian for your children who are minors or a stand-by guardian for your adult child with mental retardation.

If There Is No Will

If you die without a will, your estate, including all property in which you have an ownership interest, will usually be distributed to your heirs according to the laws of the state in which you live. This is the law of “intestate succession.” It was not designed for families that include a member with mental retardation. Although this inheritance law can differ from state to state, it basically requires that an estate be divided in various shares among the family. If a parent of a child with mental retardation dies without a will, that son or daughter may inherit property under intestate succession laws. This may result in a distribution of assets which may be mismanaged, jeopardize government benefits or result in cost-of-care charges.

Contents of the Will

Your written will determines several legal events after your death. A will:

- Lists people to serve as your personal representative in order of preference. The personal representative (sometimes called the executor) inventories the decedent’s (the person who has died) assets, ensures payment of taxes, distributes property as specified by the will and accounts to the court.
- Lists people, in order of preference, you want to be guardian of your personal matters and/or guardian of your minor children’s property.

- Lists people, in order of preference, you want to be guardians of your minor children or grown child with mental retardation if such a guardianship is needed.
- Lists people, in order of preference, you want to serve as trustee of any trust in your will.
- States any specific property or money gifts to special people or groups. This would include family members, other people and any special bequests to a charity, religious group or other organization.
- States which family members, people or groups should get the remainder of your estate. You can divide the estate distribution into various amounts, shares or percentages.
- States how you would like assets left to your son or daughter with mental retardation by placing assets in a trust in terms set down in your will, or by placing assets in an existing trust already set up for your son or daughter with mental retardation.

A will has no legal effect and can change until the moment of death of its maker. However, each new or changed will must meet all the requirements outlined below.

Legal Requirements

In most states, a will must meet certain requirements for legal enforcement:

- The will must be a written document. Merely speaking your intentions and appointments are not legally valid.
- The person who makes the will must be an adult and have a “sound mind” (legally competent).
- The decisions in the will must be voluntary. No one can legally force or coerce a decision in a will.
- The maker must sign the will before two or three witnesses who do not have any interest in the estate. These witnesses must also sign the will in the presence of the maker and each other.

Special Provisions

Regardless of the estate plan options chosen, the will should state that one or more family survivor has a disability. This establishes a factual basis in the will for the special planning that needs to be done.

In almost all cases, parents, grandparents and other relatives should consider making arrangements to the effect that the family member who has mental retardation does not own or receive legal title to the parents’ or relatives’ money, real estate or other assets whether transferred by will, inheritance or gift. The person with mental retardation should not be designated as a direct beneficiary of any life insurance policy.

If a burial fund for the child with mental retardation has not been established, the will can be used to set one up. This can be done in the child’s name in a way that is not countable against any federal or state benefits.

Other Considerations Related to a Will

Limitations

There are some limitations to wills. For example, they do not change your life insurance terms, some retirement plans or contracts. The proceeds from insurance and retirement would go to the person named as beneficiary. Contracts are legally binding documents that must be honored even after your death. Jointly owned property would also pass on to the other owner(s) under what is called the “rights of survivorship.”

Married parents usually own property together under which rights of survivorship applies. Therefore, a will of the first parent to die may not have much legal importance when there is joint property. The remaining spouse would become sole owner and may decide to change the distribution of this asset. Since you cannot predict which parent may die first, both parents should have their own will. You should design wills so the financial plan for your child with mental retardation becomes effective regardless of which parent dies first.

Appointment of Guardian

As discussed in the last chapter, most states allow you to nominate a guardian for your minor children if you should die and no natural guardian is living. You can nominate guardians for your son or daughter if there is already a guardianship in place. However, a person you nominate may not be able to act as guardian due to unforeseen circumstances. The court may also decide not to appoint that particular person. Usually the court will accept your selections, but there may be a situation where they will not. This is why it may be good to have a list of preferences.

Your will provides the court with your expectations. However, you should talk to those individuals whom you are nominating to act as guardian for either your minor children or your grown child with mental retardation. These individuals should be aware of the responsibilities and be willing to accept the responsibilities of a guardian.

Differences in State Laws

Some people will live in several different states before they die. As a result, they may prepare a will while living in one state, but die as a resident of another state. Usually, the will prepared in one state is valid in another. However, if this might be your situation, consider the following:

- Always have your last will reviewed and, if necessary, revised when you move to another state.
- Property ownership laws do differ throughout the United States. If you own property in different states, have an attorney trained in the laws of the state where you own property review your last will. These property issues not only apply to real estate, but also to other property such as bank accounts and business investments.
- You may be a legal resident of a state which is different from your child’s state of residence. In this case, you may also need the advice of an attorney trained in the laws of the other state. This is especially true if your will contains a trust for that child.

Periodic Review

It is very important to review the will periodically to determine whether it still reflects the individual's wishes and the child's current and prospective circumstances. Changes in the will may be required by the death of a spouse, changes in economic condition, the progress of the child with a disability, the availability of a successor guardian, divorce and other general changes in the family's circumstances.

Changes in the will also may be required as changes occur in the laws relating to taxes, trusts, wills, governmental benefits and financial assistance. It is recommended that spouses individually review their wills each year and have them reviewed by an attorney at least every five years.

Divorce and Remarriage

In most states, a divorce revokes any provisions in your will made for your former spouse. However, it is still a good idea to rewrite your last will to clear up any misunderstandings. Divorced parents of a child with mental retardation may have a special and complicated legal problem. Divorced parents still need to coordinate asset plans and guardianship expectations for their child.

Another marriage creates special legal ownership rights for the new spouse. These ownership rights can overrule your last will and destroy, change or weaken the plan made for your child with mental retardation. To protect and maintain flexibility in planning, the divorced parents of a child with mental retardation need to seriously consider a pre- or post-marriage (prenuptial or post-nuptial) agreement. This is a legal agreement between the two people marrying (or already married if the new spouse is willing to sign). It is to prevent the new spouse (or spouse's heirs) from undoing the financial planning accomplished for the child with mental retardation. Family members or others can dispute these agreements; but, if done correctly, these agreements do increase the protection of planning done for your son or daughter.

Letter of Intent

A letter of intent communicates and documents your preferences to others. It provides a guideline to others who may become responsible for decisions about your child.

The letter of intent is a personal letter drafted by you, the person making a will. Your letter will express your preferences in services, supports and other personal areas about your son or daughter. This letter differs from the will because it does not convey legally binding directions like those in a will. Rather, it is a personal letter to those people who will have responsibility for your child with mental retardation when they must make important decisions.

Important points to remember when writing this letter are:

- Parents, brothers, sisters, other family members and especially the person for whom the letter is intended should contribute to the letter.
- The contents of your letter should reflect your expectations. Future circumstances may make it difficult for others to carry out strict demands for your son or daughter with

mental retardation. You must trust that those carrying out your plan will try to adhere to your expectations.

- You should gear the preferences in the letter toward enhancing your son or daughter's independence and growth. Your requests should not be for the convenience of other family members or service providers.
- The letter should be written in non-technical language by the parents. It should communicate to the reader your heartfelt desires for your son or daughter.
- A letter of intent is not legally binding like a will. However, its content should not contradict your other legal documents. Have your attorney read the letter to be sure it agrees with the will.
- Periodically review and, if necessary, update your letter. Make sure it still reflects not only your expectations, but also the preferences of other family members and your son or daughter with mental retardation. Age and changes in other circumstances may alter what you want in the letter.

Your letter should begin by stating the individual's full name, date of birth, place of birth and Social Security number. You should also name the agencies that relatives, trustees and guardians should contact for advice and help (e.g., local chapter of The Arc, certain attorney, adult protective services). Other items to describe in the letter may include:

Financial and other supports:

- Government benefits which the person receives or may be eligible to receive.
- Any arrangements with a corporate guardianship or cooperative master trust program for your son or daughter's continued care. Include the program's name and location plus any special instructions for this program.
- Your son or daughter's current employment or the type of employment you think he or she would like.

Living arrangement:

- The type (e.g., live with a particular relative, small group home, apartment with support).
- Location
- The qualities of the living arrangement (e.g., non-smoking home, adhere to a certain religion).

Programs/services

- The type of school or day program setting expected.
- The type of services, therapies or medical interventions that are needed or may be needed (e.g., job training, speech therapy).
- Routine medical care (e.g., regular check-up, annual eye examination) and the names and locations of preferred medical professionals. Include any health insurance that should be maintained.
- Regular routines in the person's schedule (e.g., daily schedule of getting ready for school, weekly appointments).

Personal preferences

- Grooming and hygiene preferences (e.g., type of clothes, hair style, preferred toilet articles).
- Likes and dislikes about food, chores and other areas.
- Favorite personal items (e.g., personal radio, certain furniture).
- Personal habits important for someone else to know about.
- Friends and close relatives, their locations and how often your son or daughter likes to visit those people.
- Favorite recreation and other leisure activities and your son or daughter's level of independence in these activities. Include how often this person likes to participate in activities.
- Your son or daughter's religious preferences and how often he or she participates in religious activities.

Abilities

- Level of independence in getting around the community (e.g., ability to ride public transportation, independence in shopping).
- Abilities in handling money (e.g., change-making, independence in purchasing items).
- Abilities in reading, writing, communicating and understanding what others may tell him or her. If your child does not use verbal communications, note how he or she communicates desires or replies to others.

List any other information that is important for your son or daughter. Both parents should sign the letter. After having your attorney review the letter, keep a copy for yourself and a copy with your legal will. Distribute the letter to those who may be responsible for decisions about your child.

Letter of Last Instruction

The letter of last instruction is somewhat similar to the letter of intent. It is an actual letter written by you outlining to your family, friends or attorney what to do immediately upon your death. It contains instructions on areas that may need attention between the time you die and the reading of your will and letter of intent.

The reading of the will and letter of intent are usually done some time after a person's death. So, a letter of last instruction usually contains information requiring immediate action. For example, it may describe your desire for certain funeral arrangements, list whom to inform about your death, tell where important documents are and describe how to care for your child with mental retardation immediately upon your death.

Some people prefer to include the letter of last instruction with the letter of intent. However, the letter of intent in this case refers directly to the longer term care of your child with mental retardation. For this reason, you should draft a separate letter of last instruction.

Include in your letter:

- The person who should tell your son or daughter of your death and if your child should attend the funeral.
- If necessary, the person expected to care for your son or daughter immediately after your death or until your letter of intent or will can be implemented.
- If your son or daughter is not living with you at the time of your death, where he or she lives.
- Arrangements with a corporate guardianship or cooperative, master trust program (pooled trust). Include its name and location plus the location of any additional documents about this arrangement.
- Your desired funeral arrangements.
- If you have pre-arranged a funeral, list the funeral home and cemetery's name and location, plus the location of the funeral document.
- People to notify about your death and funeral. Include their names, addresses and phone numbers.
- The names of organizations or specific causes you desire people make donations to if they so wish.
- The location of important documents, especially your will and other important papers. If these documents are in a safe deposit box or other such location, give the name, location and account number. Include the names of people who have legal access to the box.
- The name and location of the attorney whom you wish to handle your legal affairs.
- Any wishes you may have to make an organ donation. (Note: Some states may require specific documents or procedures for people wishing to donate organs.)
- Other last instructions you may have before the reading of the will or letter of intent.

Once written, have your attorney review your letter of last instruction to make sure it does not contain information contrary to your other wishes. Leave a copy of this letter with several family members and your attorney. Write on the envelope that the letter is to be read immediately on your death. You should sign the letter, but it is not legally binding and does not need notarization.

Will Resources

Disabilities Law Project. (2003). *Estate Planning for Families of Persons with Disabilities*. Philadelphia, PA. Available on-line:
http://www.dlp-pa.org/pubs/Estate_Planning_May_2003.pdf

CHAPTER 6 GOVERNMENT BENEFITS

Supplemental Security Income (SSI)

SSI is a federal income supplement program funded by general tax revenues (not Social Security taxes). It is designed to help people who are aged, blind, and disabled who have little or no income. It provides cash to meet basic needs for food, clothing, and shelter.

SSI benefits are not based on an individual's prior work or a family member's prior work. To get SSI, a person must have limited income and resources. In most states, SSI recipients also can get Medicaid (medical assistance) to pay for hospital stays, doctor bills, prescription drugs, and other health costs. SSI recipients may also be eligible for food stamps in every state except California.

To get SSI, a person must be at least 65 years old, or be blind or disabled. An adult must be unable to work due to a physical or mental impairment which has lasted or is expected to last at least 12 months or result in death. A child under age 18 is eligible if he or she has a physical or mental condition or conditions that can be medically proven and result in marked and severe functional limitations, and the condition(s) must have lasted or be expected to last at least 12 months or end in death. If age 18-22 and a student, the adult disability definition applies.

Because SSI is an income support program, monthly eligibility is based on the financial need of an eligible individual. Congress established a threshold amount that it says is the amount of federal support people need for food, clothing and shelter. Called the federal benefit rate (FBR), this amount is adjusted every year for cost-of-living changes. In 2004, the FBR is \$564. In some states, the federal payment is supplemented to make up for regional living costs.

Income considered in determining SSI eligibility includes earnings from employment, pension, alimony, interest, and food, clothing and shelter given on a regular basis. Any amount of money that is given as a gift or inheritance is counted as income. These are some of the reasons to consider a special needs trust for individuals with mental retardation and related developmental disabilities. Resources are assets that the individual owns such as cash/bank accounts, life insurance, land and personal property. To qualify for SSI, an individual is allowed to have assets of no more than \$2,000. Owning a home is allowed if the person lives in it, as is a car if it is needed for work or medical treatment and for other specified reasons. The face value of a life insurance policy cannot exceed \$1,500. Certain types of resources do not count, such as food stamps, energy assistance and federally subsidized housing.

Social Security Disability Insurance (SSDI)

Social Security Disability Insurance (SSDI or DI) is a federal disability insurance program funded by a portion of the Social Security FICA taxes a worker and employer pay on a worker's earnings. An eligible worker who is disabled can receive monthly cash payments to replace some of his or her lost income and Medicare medical supports. Medicare provides medical coverage beginning two years after the benefits start.

SSDI differs from SSI in that it is not based on financial need. It may be based on your child's own work record or on the parent's work record. For a child with a disability to receive benefits on the parent's work record after age 18, the following rules apply:

- The disabling impairment must have started before age 22, and;
- He or she must meet the definition of disability for adults.
- The parent who paid in to Social Security must become disabled, retire or die in order for the disabled adult child to receive benefits.

NOTE: An individual may become eligible for a disabled child's benefit from Social Security later in life. This is called Disabled Adult Child benefit (DAC). For example, a worker may retire and start collecting Social Security retirement benefits at age 62. He has a 38-year old son who has had cerebral palsy since birth. The son will start collecting a disabled "child's" benefit on his father's Social Security record. To be eligible for DAC benefits, the individual must be an unmarried child of a person already receiving SSDI, Retirement Benefits, or who died while covered by Social Security. The child's benefit is equal to 50% of the parent's Social Security when the parent retires and 75% of the parent's Social Security when s/he dies. A person receiving only DAC benefits can have unlimited assets and so can receive an inheritance without affecting DAC benefits.

Disability under your own Social Security is based on your inability to work. You are considered disabled under Social Security rules if you cannot do work that you did before and you cannot adjust to other work because of your medical condition(s). Your disability must also last or be expected to last for at least one year or to result in death.

To qualify for benefits, you must first have worked in jobs covered by Social Security. Then you must have a medical condition that meets Social Security's definition of disability. In general, Social Security pays monthly cash benefits to people who are unable to work for a year or more because of a disability.

Benefits usually continue until you are able to work again on a regular basis. There are also a number of special rules, called "work incentives," that provide continued benefits and health care coverage to help you make the transition back to work. If you are receiving Social Security disability benefits when you reach age 65, your disability benefits automatically convert to retirement benefits, but the amount remains the same.

In addition to meeting the Social Security Administration's definition of disability, you must have worked long enough--and recently enough--under Social Security to qualify for disability benefits. Social Security work credits are based on your total yearly wages or self-employment income. You can earn up to four credits each year. The amount needed for a credit changes from year to year. The number of work credits you need to qualify for disability benefits depends on your age when you become disabled. Generally, you need 40 credits, 20 of which were earned in the last 10 years ending with the year you become disabled. However, younger workers may qualify with fewer credits.

Children and Disability Benefits

Under the SSI program, a child from birth to age 18 may receive monthly payments based on disability if he or she has an impairment or combination of impairments that meet the definition of disability for children. The family must have limited income and resources to qualify. (See SSA Publication No. 05-10026 in Resource section.)

Children under age 18 may also receive Social Security dependents benefits based on the record of a parent who is collecting retirement or disability benefits from Social Security, or survivors benefits based on the record of a parent who has died. This benefit is not based on the child's disability. However, those benefits can continue to be paid into adulthood if the child is disabled. To qualify for these benefits, an individual must be eligible as the child of someone who is getting Social Security retirement or disability benefits, or of someone who has died, and that child must have a disability that began prior to age 22.

Medicaid

Medicaid is a health insurance program for low-income individuals who meet the other eligibility criteria set by the federal government such as having a disability. It is a federal-state program that varies from state to state. It is run by state and local governments within federal guidelines. All states cover a minimum set of services including hospital, physician and nursing home services. States have the option of covering an additional 31 services including prescription drugs, hospice care and personal care services.

Since it is a "needs-based" program, most individuals who qualify for SSI will qualify for Medicaid. In many states, this is an automatic process. In others, the individual must submit a separate application for Medicaid.

It is important for families to know that Medicaid, in addition to providing health care, is the funding source for the majority of other services offered in the developmental disabilities system. Almost all residential services are funded through Medicaid. The Medicaid Home and Community-Based Services (HCBS) Waiver funds such services as supported living, supported employment and family support.

The Home and Community-Based Services Waiver legislation provided a vehicle for states, for the first time, to offer services previously offered in institutional settings to serve people in their own homes and communities. HCBS waivers afford States the flexibility to develop and implement creative alternatives to placing Medicaid-eligible individuals in hospitals, nursing facilities or intermediate care facilities for persons with mental retardation.

The Act specifically lists seven services that may be provided in HCBS waiver programs: case management, homemaker/home health aide services, personal care services, adult day health, habilitation, and respite care. Other services, requested by the state because they are needed by waiver participants to avoid being placed in a medical facility (such as non-medical transportation, in-home support services, special communication services, minor home modifications, and adult day care) may also be provided, subject to federal Center for Medicare & Medicaid Services (CMS) approval. The law further permits day treatment or other partial

hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness.

Medicare

Medicare is a federal health insurance program. Medical bills are paid from trust funds which those covered have paid into. It primarily serves people over age 65, whatever their income, and serves younger disabled people and dialysis patients. Beneficiaries who are disabled are eligible to receive Medicare after a two-year waiting period.

Medicare has two parts – Part A (hospital insurance) and Part B (medical insurance). Part A is paid for by a portion of the Social Security tax of people still working. It helps pay for inpatient hospital care, skilled nursing care, and other services. Part B is paid for by monthly premiums of those who are enrolled. It helps pay for such items as doctor's fees, outpatient hospital visits, and other medical services and supplies.

Dual eligible beneficiaries who are also eligible for Medicaid can receive additional assistance from their State Medicaid program. For example, most Medicaid programs will pay the Part B premiums. Medicaid will also supplement Medicare coverage by providing services and medical supplies that are not covered by Medicare. Services that are covered by both programs will be paid first by Medicare and the difference by Medicaid, up to the State's payment limit. Medicaid also covers additional services (e.g., nursing facility care beyond the 100 day limit covered by Medicare, prescription drugs, eyeglasses, and hearing aids).

Applying for Benefits

An initial application for disability supports under the Social Security program should be made at your local SSA office (call 1-800-772-1213 to find the office nearest you). Applicants for SSDI benefits (but not SSI or children's benefits) can now apply online by going to <http://www.ssa.gov/applyforbenefits/> and following the instructions.

No application for disability benefits is completed until a written and signed application is submitted. Likewise, one cannot be officially denied or awarded benefits until that written application is reviewed by SSA and a formal decision has been made. SSA may get some of the initial application information by phone, but it is best to complete a written application for disability benefits as soon as possible.

You should have a knowledgeable advocate who understands Social Security policies to assist you in completing the complicated application. Submitting a signed, written application provides documentation of the application date. This date is very important should an SSA decision need to be appealed. If the appeal is successful, benefits can start on the documented "protected" date when the application was made.

Resources on Government Benefits

Scarborough, D. (1990-2003). *Accessing Social Security Disability Benefits to Provide Vocational and Educational Opportunities for People with Disabilities*. National training curriculum for disability service organizations on accessing Social Security disability programs. Available from author, d.scarborough@passNetwork.org.

Scarborough, D. (2003). *Appealing a Decision by the Social Security Administration for Disability Benefit Eligibility*. The Arc of the United States. Available on-line: <http://www.thearc.org/afesp/appeals.htm>

Scarborough, D. (2003). *How the Social Security Administration Defines Disability for Social Security Disability Benefit Eligibility*. The Arc of the United States. Available on-line: <http://www.thearc.org/afesp/defdisability.htm>

SSA Publication No. 05-10029. *Disability Benefits*. February 2003, ICN 456000. Available on-line: <http://www.ssa.gov/pubs/10029.html>

SSA Publication No. 05-10026. *Benefits for Children With Disabilities*. August 2001. Available on-line: <http://www.ssa.gov/pubs/10026.html>

Social Security Disability Insurance (SSDI) Program: <http://www.ssa.gov/disability/>

Supplemental Security Income (SSI) Program: <http://www.ssa.gov/notices/supplemental-security-income/>

CHAPTER 7

PREPARING TO WORK WITH AN ATTORNEY

By now you have become familiar with wills, trusts, government benefits, letters of intent, guardianship and other parts of a plan. You have put thought to your plan, discussed it with family and others and gathered your important documents together. You are now ready to see your attorney to put your plan into proper legal order. To make sure you have your thoughts and paperwork in order, review the Planning Checklist at the end of this chapter.

An attorney is an essential part of good planning. It is this professional who will help guide you through the steps in planning, advise you appropriately and prepare your documents in proper legal language.

Some families may already have an attorney who is both capable and familiar with the laws involving trusts, guardianship and disability. However, most people will have to seek out an attorney for assistance. In either case, you should make sure you feel comfortable that your attorney is knowledgeable about the special issues concerning your family member with a disability and will charge you fairly for the legal work performed.

Selecting an Attorney

Effective planning for your son or daughter involves special legal problems not found in routine estate planning. These may include asset planning, guardianship and knowledge of the programs and benefits available for a person with mental retardation. Some attorneys are not aware of the legal issues associated with these areas. If your current attorney does not have this type of experience, consider asking for a referral to another attorney who specializes in future planning for people with disabilities. You might also find an attorney by asking other parents, contacting your local or state chapter of The Arc or asking bank trust officers for a referral. Another source of information is the state or local bar association. Some have attorney referral services.

Attorney Fees

At the first meeting with your attorney, ask about the fee arrangement for the legal services. Some attorneys will charge on an hourly basis. Others will charge a fixed fee for the project. An experienced attorney should be able to explain the cost of legal services for your asset planning, will and other legal work. Even attorneys who charge on an hourly basis should give you a cost estimate for this service. If the attorney is vague about fees, then this person may not be appropriate to handle your work. You should also ask the attorney about future fees for handling a possible guardianship, administering an estate or assisting a trustee. These matters require continuing services from an attorney, so make sure the charges for future services are fair and appropriate.

Evaluating Your Attorney

Comparing legal fees alone is not the best way to evaluate the quality of legal services. Your first visit with an attorney should be to determine if this professional is both knowledgeable and sensitive to this type of planning. Here are some things you should look for:

Does the attorney

- Give you direct complete answers to your questions?
- Explain laws and regulations in a way you could understand?
- Appear concerned and interest in your situation?
- Demonstrate a good understanding of mental retardation and other cognitive impairments?
- Demonstrate a good understanding of disability-related legal issues (i.e., Medicaid, etc.)?
- Have experience handling future planning cases?
- Give you a good timetable for completing all your legal work?
- Give you a good explanation of the costs of the legal work?
- Demonstrate respect for your son or daughter with a disability?

When the meeting ends, you do not have to agree to retain or use this attorney's services on the spot. You may wish to visit with your spouse or others who may have accompanied you. If you agree to retain this attorney, you should get a clear picture and timetable for completing your plan. It should not be necessary to keep contacting your attorney to get the legal work completed. Do not hesitate to talk to your attorney if you think there may be problems.

Revising Your Plan

Once completed, you should periodically review and revise your plan, perhaps every three to five years. However, any major change in circumstances may signal it's time to review your plan. For example, if you drafted your plan for your daughter when she was eight years old and she is now nearing adulthood, it would be a good time for a review. A person nearing adulthood faces legal changes of status and has different needs from a minor. Other situations signaling a need for a review may include a move to a different state, a marriage, divorce or a parent's death. Coming into a large sum of money or facing some severe financial set-back may also require a change in the plan.

If situations, finances, family circumstances or other factors require a revision, then contact your attorney or other necessary professionals to make the change. Do not let your plan become obsolete to the point where it is either ineffective or perhaps even counterproductive to your family member.

Resources for Locating an Attorney

The Commission on Mental and Physical Disability Law. Disability Law Directory.

<http://www.abanet.org/scripts/disability/displaySearch.jsp>

Planning Checklist

Before Going to the Attorney

Financial Information

Have you completed an asset inventory?	Yes	No
Do you have copies of automobile titles, home deeds and other assets you listed?	Yes	No
Do you have copies of your stocks and bonds certificates?	Yes	No
Do you have copies of all your insurance policies?	Yes	No
Do you have copies of all you pension plans?	Yes	No
Do you have copies of any paperwork on large debts?	Yes	No
Do you have copies of existing trust information?	Yes	No

Will Information

Do you have a copy of your will (if you have one)?	Yes	No
Have you completed your letter of intent?	Yes	No
Have you completed your letter of last instruction?	Yes	No

General Information

Do you have copies of your and your family member's Social Security Cards?	Yes	No
Do you have copies of program information in which your family member is involved?	Yes	No

After Completing Your Plan

General Information

Do you have a secure place such as a safe deposit box to keep your important documents and plan?	Yes	No
Have you made copies of important papers which are considered legally valid (usually called "true copies")?	Yes	No
Do family members or other significant people know of your plan and/or have access to your letter of last instruction and other documents?	Yes	No



POSITION STATEMENT



GUARDIANSHIP

POLICY STATEMENT

The majority of people with mental retardation and related developmental disabilities¹ can manage their own affairs with informal assistance and guidance from others, such as family and friends. If guardianship² is necessary, it should be tailored to the person's needs. It must be adequately monitored to ensure that the best interests of the individual are protected.

ISSUE

The appointment of a guardian is a serious matter because it limits a person's independence and rights. Guardianship has been over-used by those who were unaware of less intrusive alternatives or who simply wanted to have their views prevail over the wishes of the individual. Frequently, lesser forms of legal intervention such as limited guardianship and use of powers of attorney have been either overlooked, intentionally avoided, or unavailable.

POSITION

The majority of our constituents can manage their own affairs with informal assistance and guidance from family, friends, and others. If guardianship is essential, it should be used only to the extent necessary with a presumption in favor of limited rather than full guardianship.

Systems Issues

- Appointment of a guardian should be made only to the extent necessary for the protection and welfare of the individual and not for the convenience of the family, the service system, or society.
- Less intrusive alternatives to full guardianship, like limited guardianship or power of attorney, should always be considered first. If used at all, these restrictions on the individual's rights and decision-making powers should be confined to those areas in which the individual clearly cannot understand the serious consequences of his or her decisions or the person lacks foresight.
- Mechanisms to reverse unnecessarily restrictive forms of existing guardianship must be available.

¹ "People with mental retardation and related developmental disabilities" refers to our constituency, *i.e.*, those defined by the AAMR classification and the DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

² Terminology for guardians differs by state and can include tutor, conservator, etc.

- Since guardianship represents a transfer of the responsibility for exercising an individual's rights, adequate safeguards, including the right to counsel, are needed to assure the individual retains as much decision-making power as possible.
- Members of the judiciary and attorneys need training on alternatives to guardianship for our constituents
- Individuals placed under guardianship must have legal representation at all stages of the process and must be informed about the possibility and the process to have the guardianship removed

Guardian Responsibilities

- They should be knowledgeable of services, supports, and systems that could significantly affect the life of the individual, and must be committed to the well-being of the individual, know and understand the individual's needs and wishes, and act in accordance with them whenever possible. Family members are preferable when they meet these criteria.
- They shall take the person's preferences into account.

Oversight

- States should adopt minimum standards for all guardians and require that training and technical assistance be made available.
- Professional guardians (those who serve two or more wards who are not related to each other and receive fees) should be licensed, certified, or registered and should have the appropriate education and skills. They should not be receiving payment for providing other services to the ward.
- The guardians shall be accountable for their actions, and those actions must be reviewed periodically.

Adopted: Board of Directors, AAMR
May 28, 2002

Congress of Delegates, The Arc of the United States
November 9, 2002

Resources
Rehabilitation Research and Training Center on Aging
with Developmental Disabilities

Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTCADD) web site: <http://www.uic.edu/orgs/rrtcamlr>

As persons with intellectual and developmental disabilities are living longer and their presence in the community increases there is a growing need for information on ways to support these adults and their families. This web site is designed to provide information on the latest research, model programs, and policy issues pertaining to this population. It describes training and technical assistance opportunities, conferences, and available resources. These resources are available in various formats, including written products, videotapes, and CDs. Many of the products can be downloaded at no cost. We tried to design a user friendly website not only for researchers and professionals, but also for families and persons with a disability. We welcome your suggestions.

The following RRTCADD products are useful resources for families and staff engaged in the future planning process. For more information, please contact the RRTCADD at 1-800-996-8845 (V) or 1-800-526-0844 (IL Access)

The future is now: A future planning training curriculum for families and their adult relatives with developmental disabilities, (2003). Debrine, E., Caldwell, J., Factor, A., & Heller, T.

This curriculum equips families and their adult relative with a disability with the communication skills and information to jointly plan for the future. Participants learn how to overcome the emotional and systematic barriers to planning with the support of peer mentors who have made plans. They prepare a letter of intent that lays out their dreams for the future and identifies the steps required to transform this dream into a reality. This state-of-the-art approach to future planning was developed, implemented and evaluated by the RRTCADD. It is an excellent resource for agencies, family organizations and advocacy groups.

ITEM NO: 100.018 COST PER UNIT: \$50.00 (Softcover)
ITEM NO: 100.017 COST PER UNIT: \$25.00 (CD-ROM)

Future planning resource guide for families and adults with developmental disabilities in Illinois, (2002). Caldwell, J., Lopez, E., DeBrine, E., Factor, A., Heller, T., & Ennis, D.

This guide helps families navigate the maze of adult services and supports for individuals with developmental disabilities. It responds to families' need for a centralized source of information that

describes adult services and how to access them. Content includes an overview of the service system and information on legal and financial planning, vocational and residential services, community supports, recreation and leisure opportunities, transportation, and advocacy. Information is in a user-friendly, question-and-answer format that was recommended by families. The guide is a template that other communities can follow in providing information on local services.

ITEM NO: 100.019 COST PER UNIT: \$35.00

Can be downloaded at no charge from: www.uic.edu/orgs/rrtcamr

Person-centered planning for later life: Death and dying - A curriculum for adults with mental retardation, (2000). Sterns, H.L., Kennedy, E.A., & Sed, C.M.

This training curriculum helps adults with mental retardation understand death, dying and loss. It covers the concept of death; experiencing and coping with grief, mourning, comfort, and support; and death-related rituals (visitations and funerals). The curriculum consists of **five in-class lessons** and **one field trip**, which emphasize active participation through both verbal and visual presentation of materials. The **instructor's guide** provides a script for each lesson and includes guidelines for planning and administering each lesson. Each participant has a **student notebook** that accompanies the instructor's training curriculum. Each participant chooses a support person to help him/her review the lessons and complete assignments.

ITEM NO: 100.014 Instructor's Guide COST PER UNIT: \$25.00 for Guide and Notebook

ITEM NO: 100.015 Student Notebook (Additional Student Notebooks are \$12.50 each).

Promoting healthy aging, family support, and age-friendly communities for persons with developmental disabilities: Report of the 2001 Invitational Research Symposium on Aging with Developmental Disabilities, (2002). Heller, T., Janicki, M, P., Hammel, J., & Factor, A.R.

This report summarizes the research to date and presents recommendations for future research, progressive policies, and innovative intervention to promote healthy aging, support aging adults and their families, and create age-friendly communities. These recommendations coalesce the thinking of the 100 plus international researchers, service providers, families and persons with disabilities who participated in the conference.

ITEM NO.: 600.017 COST PER UNIT: \$10.00 per bound copy.

Can be downloaded at no charge from:

www.uic.edu/orgs/rrtcamr

Aging with developmental disabilities: An information packet on understanding age-related changes and supporting successful aging, (1997). Factor, A.

This packet provides a basic understanding of age-related changes and their implications for adults with developmental disabilities and their families. Topics include: the aging process and its implications; supporting individual choice and community membership; and engaging and supporting older families in making future plans for their relative with a disability. It contains guidelines and practical suggestions for supporting individual choice and community membership, healthy aging and family future planning.

ITEM NO: 920.001 COST PER UNIT: \$15.00

Aging family caregivers: Needs and policy concerns, (2000). Heller, T. Family Support Policy Brief #3. National Center for Family Support.

This policy brief discusses the needs of aging caregivers, including planning for the future of their relative with a developmental disability. It addresses cultural differences in family caregiving and trends in family support policies.

ITEM NO.: 310.013 COST PER UNIT: \$3.00

The Tampa Scientific Conference on Intellectual Disability, Aging, and Health: Final report, (2003). Davidson, P.W., Heller, T., Janicki, M, P., & Hyer, K.

This report identifies the gaps in knowledge about the health of older persons with intellectual and related developmental disabilities. It contains a research agenda for health and mental health outcomes based on the recommendations of the 75 researchers, health professionals, older adults with disabilities, and families who participated in this international conference.

**ITEM NO.: 520.028 COST PER UNIT: \$10.00 per bound copy.
Can be downloaded at no charge from:**

www.uic.edu/orgs/rrtcamr