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Transition Planning ~ Guardianship and Future Planning

- Guardianship in MA—An Overview (Source: Atty. Eileen Sullivan-Boss)
- Future Planning: Guardianship (The Arc)
- The Special Needs Trust—Planning for the Future of Your Loved One with a Disability (by: Richard Fee)
- Planning for the Future (ASA)
- Building a Future Requires Vision, Planning (Source: Newslines)

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a division of THE ASSOCIATION FOR COMMUNITY LIVING

*Creating Opportunities, Building Relationships, Improving Lives
for children and adults with developmental disabilities since 1952*

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GUARDIANSHIP
IN
MASSACHUSETTS

Attorney Sullivan-Boss focuses her practice in the areas of Guardianship, Disability and Elder Law. She is an active member of the National Guardianship Association and the National Association of Elder Law Attorneys. Attorney Sullivan-Boss was recognized by the Commonwealth of Massachusetts in 2003 for her service to disabled individuals and their families.

AN OVERVIEW FOR FAMILY
AND VOLUNTEER GUARDIANS

What is a legal guardian?

A legal guardian is a person or agency appointed by a Court as an advocate to guard the best interest of an individual who has been adjudicated incompetent.

When does the Court appoint a guardian?

A guardianship is necessary only after all less restrictive alternatives have been considered or attempted.

There are three statutory bases for guardianship of incompetent individuals in the Commonwealth of Massachusetts.

- Mental Illness
- Mental Retardation
- Physical incapacity to communicate informed decisions

A guardian of a minor can also be appointed when necessary.

Who can be appointed a legal guardian?

The Court will only appoint as guardian an individual who the court has determined to be suitable to so serve. A competent person over the age of 18 is generally eligible but the suitability requirements vary with the needs of the proposed ward.

Is the process of being appointed a guardian complicated?

No, but there are specific requirements for petitioning the Court and for providing notice to interested parties. The county Probate Courts have jurisdiction to appoint legal guardians for incompetent individuals and the process is defined by the law and rules of the Massachusetts Probate and Family Courts. The required forms are available at the clerk's office of any of the Probate Courts in the Commonwealth.

How long does a guardianship last?

The guardianship should last only so long as it is necessary. When the ward has regained or achieved capacity to make informed decisions, notice is provided to the Court and the guardianship can be modified, restricted or terminated.

Does a guardian manage medical or financial decisions for the ward?

A guardian can be appointed "of the person only" or "of the person and estate." A guardian of the person and estate manages the ward's finances and is required to submit annual accountings to the Court.

Does the process of being appointed a guardian always take a long time?

In most situations, the process of appointing a guardian does take several months to complete. In an emergency situation, though, the Court can appoint a temporary guardian immediately. The term of the temporary guardianship is ninety days.

Does a guardian make all decisions for the ward?

No. The ward is not stripped of all decision-making rights by guardianship. Some examples of rights retained by the ward include the right to vote, the right to marry and the right to free association. The guardian should allow the ward as much opportunity for choice as is possible while protecting the ward's health and safety.

Some issues, including those involving extraordinary treatment, require the Court's substituted judgment. Threat with antipsychotic medication is one example of a treatment considered extraordinary in Massachusetts.

Future Planning: Guardianship and People with Mental Retardation

by Rick Berkobien, Assistant Director, Department of Research and Program Services

What is guardianship

Guardianship is the legal power to care for another person and manage his or her affairs. Each state has its own specific laws on guardianship, but the following generally describes the guardianship laws for adults throughout the United States:

Guardianship is a legal, not medical determination. When people become adults -- including people with mental retardation -- they get all the legal rights and responsibilities of any adult. Only the courts have the authority to remove these rights. A court makes this decision 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 grounds for a guardianship, not mental retardation.

How do I decide if my son or daughter needs guardianship?

Appointing a guardian for someone with mental retardation is a serious matter. This legal status deprives the person of some rights and independence, and has the potential for abuse because of the power it gives one individual over another. However, there may be different reasons why a son or daughter with mental retardation may need a guardian. Some common reasons are:

- A person with mental retardation 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.
- The person has assets he or she cannot adequately manage. Guardianship is sometimes needed to ensure the assets are secure and used for the intended purpose, and only when money management alternatives (e.g., representative payeeship, etc.) will not provide sufficient protection.
- Before pursuing guardianship, families should first try to determine if this legal protection is necessary. They need to examine why they feel a family member may require a guardian. Then, they need to familiarize themselves with less restrictive options that may meet these needs without resorting to guardianship.

What are the different types of guardianship?

Most states have different legal protective statuses or types of guardianship. State laws also often differ in defining incapacity, interpreting the guardian's duties and qualifications, terminology, reporting, documentation, costs and other areas related to guardianship.

In most states, the different types of guardianship are commonly called:

- Guardianship of the person or property
- Full guardianship
- Limited guardianship
- Temporary guardianship

(For specific information on states' laws, review the materials in the *Future Planning Resources* list noted at the end of this *Q&A*, confer with an attorney or contact your chapter of The Arc.)

Guardian of the person or property - This type of guardianship is sometimes characterized as "guardian of the person" or "guardian of the estate." In the 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 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 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 to account periodically to the court. This guardian's duties include careful investment of the guardianship assets. Guardians who have foolishly invested their ward's money may have to pay it back from their own money. 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. However, the person under a full guardianship still retains his or her basic civil rights.

Full guardianship is useful for individuals whose mental retardation is so severe that they are not capable of making informed decisions, and should be used only after exploring the alternatives, including limited guardianship.

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 be sure it is

specific to the individual's needs. 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.

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 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 that specific situation. When the problem is resolved, the order usually ends with no permanent guardianship.

Temporary guardianship usually only applies to temporary situations such as those caused by drugs, momentary illness or special medical situations. It has limited uses for long-term, reoccurring medical situations or incapacities due to a disability. This allows family members or an agency to pursue temporary guardianship if medical or other treatment is necessary but not provided because of questionable ability to consent. Once the person has temporary guardianship and treatment is provided, the guardianship is usually reviewed to determine if it should be removed.

What is a public guardian?

There will not always be a parent, other family member or friend to act as guardian of a person with mental retardation. For these and other reasons, many states have appointed public guardians that 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, time-consuming paperwork and other duties, so must divide their time among 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 can secure an individual guardian or get the services they need elsewhere.

State resources generally finance public guardianship. Although states usually have safeguards that 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.

What is 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 guardianship responsibilities for the individual. 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 parent's estate, life insurance, United Way funding, contributions or subsidies from other organizations such as chapters of The Arc.

Before contracting with a corporate guardianship agency, parents 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.

Note: This Q&A is only a general overview of one part of future planning. Families should explore with a knowledgeable attorney or advocate the alternatives to guardianship and other aspects of planning prior to making legally binding decisions. It is highly recommended that readers also review the materials on guardianship in The Arc's *Future Planning Resources* list.

To obtain a copy of The Arc's *Future Planning Resources* a list of books, agencies and other resources that address financial and legal planning, send a request and \$2 for postage and handling to: The Arc of the United States, P.O. Box 1047, Arlington, Texas 76010.

Future Planning Resources can also be found on The Arc's World Wide Web site at:
<http://TheArc.org/welcome.html>

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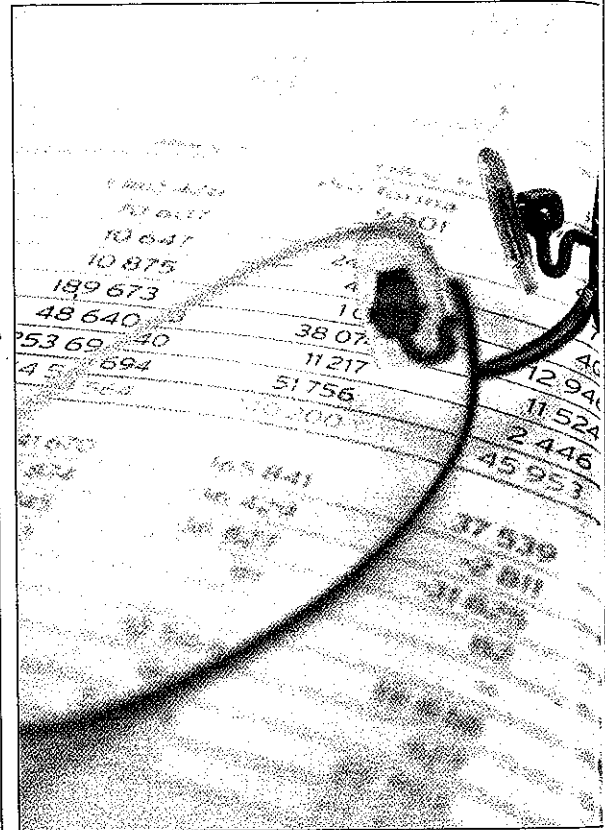
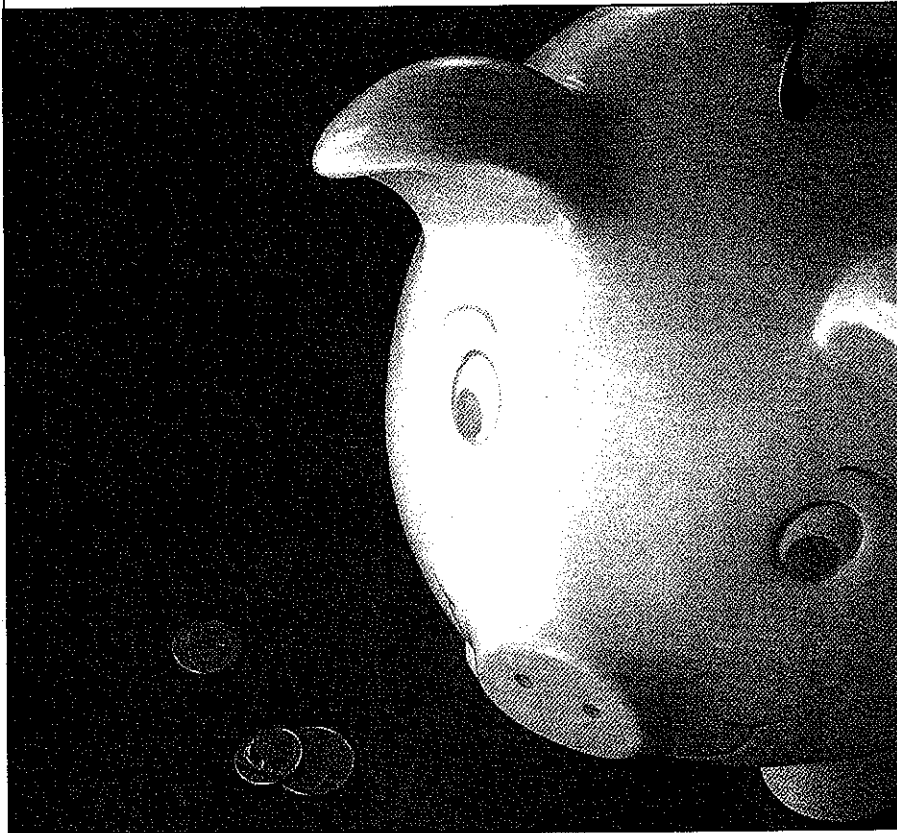
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The Special Needs Trust

Planning for the Future of Your Loved One with a Disability

BY RICHARD W. FEE, M.A., M.ED.



IMAGINE FOR A MOMENT—HORRIBLE AS IT IS TO THINK OF— THAT ONE EVENING, ON YOUR WAY HOME FROM A MOVIE OR A DINNER PARTY, YOU AND YOUR SPOUSE ARE KILLED IN AN AUTOMOBILE ACCIDENT. WHILE YOU WERE ALWAYS PLANNING TO WRITE A WILL, YOU NEVER ACTUALLY GOT AROUND TO IT, SO YOUR MODEST ESTATE, INCLUDING SOME LIFE INSURANCE, IS DISTRIBUTED BY THE LAWS OF YOUR STATE. YOU HAVE TWO SONS, ONE WITH A DISABILITY AND ONE WITHOUT. EACH OF YOUR SONS INHERITS \$100,000.

Your older son, Frank, who does not have a disability, uses his inheritance to pay off some of his mortgage and splurges on a new car. In contrast, your younger son Johnny gains nothing and loses much. Johnny, who has multiple disabilities, does not work and relies solely on government benefits for housing and medical care. The inheritance causes Johnny to lose those benefits. He must now provide for his own medical care, which includes the considerable cost of medicine, personal care attendants, physical therapy and doctor visits. The group home in which he lives begins to charge him for residency and the services he receives.

Within two years, all but \$2,000 of the inheritance is gone. At this point, Johnny again becomes eligible for government benefits and is re-instated after a waiting period of several months—a period in which he uses up the last of his inheritance. Now

there are no funds left to pay for whatever supplemental needs Johnny might have: education, over-the-counter medicines, dental care beyond what is covered by government benefits, trips to see his brother or other family members, reading materials, and basic supplies such as razors, soap and shampoo. Government benefits do not cover these types of expenses, and Johnny's parents are no longer here to do so. The irony of the situation is that, while an inheritance ordinarily improves a person's lifestyle, in this scenario, it has worsened Johnny's.

The Question of Relying Only on Government Benefits

Fairness is a primary question when something like this happens. Should the government continue to subsidize someone who has "money?" On the one hand, standard government programs such as Social Security and Medicaid were established to help the elderly and disabled living at the poverty level. On the other hand, government benefit programs are paid for out of tax dollars, and eligible individuals are entitled to receive these benefits.

When families consider this question, they should be aware that, while the services available through government benefit programs may be substantial (e.g., medical coverage through Medicaid), the actual cash benefits generally are quite small and force the person to live far below the poverty level. In 1992, the maximum federal Social Security monthly payment was \$422 for an individual. So for someone with a disability to have any type of meaningful lifestyle, the family or local charities must provide supplemental assistance.

With recent changes in the Social Security Administration, the primary government benefit programs are recognizing that family contributions to the person's well-being can only improve his overall quality of life. As long as the family's contributions are supplementary in nature, as opposed to duplicating government benefit programs, they are permitted. Thus, the current government benefit programs permit the family to provide some supplementary income and resources to the person with a disability. However, the government regulations are very strict and carefully monitored.

Special Needs Trust

A reliable method of making sure that an inheritance reaches a person with a disability is through a legal device known as a special needs trust (SNT). The SNT is developed to manage resources while maintaining the person's eligibility for public assistance benefits. The family leaves whatever resources it deems appropriate to the trust, and it is managed by a trustee (manager) on behalf of the person with the disability.

While government agencies recognize special needs trusts, they have imposed very stringent rules and regulations on them.

This is why family members contemplating using an SNT should consult an experienced attorney—not just one who does general estate planning, but one who is knowledgeable about SNTs and current government benefit programs. One wrong word or phrase can make the difference between an inheritance that truly benefits the person with a disability, and one that causes the person to lose access to a wide range of needed services and assistance. To illustrate, suppose the trust instructs the trustee to pay the person with the disability \$100 a month for life. Such a mandatory income might jeopardize government benefit programs, which only allow the person to have \$70 of earned income each month.

Families who have experience with government benefits know that the government says a person with a disability cannot have a trust. This is correct. However, the special needs trust does not belong to the person with a disability. The trust is established and administered by someone else. The person with the disability does not have a trust. Instead, he is nominated as a beneficiary of the trust and usually is the only one who receives the benefits. Furthermore, the trustee is given the absolute discretion to determine when and how much the person should receive.

Given the government's stringent requirements, covered subsequently, it is critical that the trust be carefully worded and clearly show that it:

- 1) Is established (by grantor, settlor) by the family (persons other than the person with the disability);
- 2) Is managed by a trustee (and successor trustees) other than the person with the disability;
- 3) Gives the trustee the absolute discretion to provide whatever assistance is required;
- 4) Never gives the person with the disability more income or resources than permitted by the government;
- 5) Is used for supplementary purposes only; it should add to the things provided by the government benefit program, not replace them;
- 6) Defines what it means by supplementary/special needs in general terms, as well as in specific terms related to the unique needs of the person with the disability;
- 7) Provides instructions for the person's final arrangements (families should assume that when the person with the disability dies, no relatives will be alive who know what the mother and father would have wanted);
- 8) Determines who should receive the remainder of the trust after the person with the disability dies;
- 9) Provides choices for successor trustees, people or organizations that might be able to take a personal interest in the welfare of the person with the disability; and
- 10) Protects the trust against creditors or government agencies trying to obtain funds to pay for the person's or family's debts.

Since the trust is a legal arrangement regulated by state laws, there will be other sections that your attorney may need to insert. Be aware that while the majority of public assistance funds come from the federal government (which provides guidelines for SNTs), each state government is responsible to regulate trusts and administer federal benefits. As long as the federal guidelines are followed to the letter, the state will accept the SNT, and the trust will fulfill its function.

SNTs and the Social Security Administration

The Social Security Administration's publication, "Understanding SSI," discusses special needs trusts as follows:

- ❑ How do resources in this type of trust count in the Social Security Income (SSI) program?
- ❑ If money or property in this type of trust for an SSI beneficiary does not count toward the SSI resource limits of \$2,000 for an individual?
- ❑ How does money from the trust affect the individual's SSI payments?
- ❑ If money paid directly to the providers for items other than the person's food, clothing, and shelter does not reduce SSI payments (items that are not food, clothing, or shelter include medical care, telephone bills, education, entertainment)?
- ❑ If money paid directly to the providers for food, clothing, and shelter does reduce the individual's SSI payments—how only up to a limit? No matter how much money is spent for these items, no more than \$15.00 (in 1991) is subtracted from the individual's SSI check.
- ❑ If more is paid directly to the individual from the trust, does this reduce the SSI payment?

(U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, 1990, p. 46)

Testamentary Trust vs. Intervivos Trust

At one time, the average attorney simply advised parents of an individual with a disability to prepare their last wills and testaments and include a testamentary special needs trust. Upon the death of the parents, the wills would be probated (established as authentic or valid), and the special needs trust would be created. In simpler days, this was pretty good advice.

Today, most attorneys experienced in estate planning for persons with disabilities will advise the family to prepare an *intervivos* or living special needs trust. *Intervivos* means that the trust functions now, while the parents are still living. As a "living" trust, it should not be confused with the modern estate planning tool for the family's main estate—the family revocable living trust. These are two very separate trusts. The sole function of the *intervivos* special needs trust is to look after the future of the person with the disability.

Parents need not wait until their child is 18-years-old to establish such a trust; they can establish it now. The trust is set up as a checking account at a local bank. Families can place funds into the trust every month and use these funds to cover the normal supplementary expenses of the person with the disability, as well as save for the future.

Using the *intervivos* special needs trust fund to pay for the person's supplementary expenses also is an excellent way of recordkeeping, because these expenses are tax-deductible. By paying for supplementary items from the checkbook, the family shows future trustees the types of things that are appropriate to the person's needs and that have passed government scrutiny. The typical government challenge to an SNT comes when a trustee pays for nonsupplementary items. The checkbook with stubs can help future trustees use the trust properly and avoid expensive challenges.

Sometimes, relatives (e.g., aunts, uncles, grandparents) would like to leave an inheritance to the person with the disability but are concerned that he will lose government benefits or mismanage the funds. Relatives like the concept of a trust, which is a legal way to make sure the person actually receives the full gift. With a testamentary trust, the parents of the person with the disability must pass away and their estate probated before a trust is created. Once established, relatives then can leave money to the trust. The better option is to create a living special needs trust, permitting relatives with tax concerns (i.e., those who need to give money each year to avoid large estate taxes upon their death) to give money to the trust now, rather than only upon their deaths.

Another consideration is that, according to current estimates, 40%-60% of the population will go into a nursing home before they die. The average family's total estate likely will be used up in one year to cover nursing home costs. In their wills, parents may have generously given everything to the testamentary trust. Unfortunately, after nursing home care and Medicaid expenses, there may be no estate left for the testamentary trust. And even if a portion of the estate remains after the parents die, there may be a six-month to six-year waiting period while the estate is being probated. A testamentary trust would not be created or funded during this waiting period, so supplementary needs would be unmet.

Having a living special needs trust creates a more secure scenario for the person with the disability. The parents would have saved money each month for the future and may have purchased life insurance or transferred assets into the trust. Should they suddenly pass away or enter a nursing home, the living trust continues to function without interruption. The successor trustee designated by the parents would begin to administer the trust funds within one to two hours. Supplementary assistance to the person with the disability would continue without a break.

Revocable vs. Irrevocable

Once the basic details of the trust have been agreed upon, you have to decide whether to lock the door and throw away the key, making it impossible to change the trust (irrevocable), or to hold the key just in case you want to make some changes (revocable). With a revocable trust, you retain the right to add and subtract assets as you go along. With this right, however, there are some potential consequences. The first and major consequence is that the government considers the trust to be part of your estate. Therefore, when you die, everything in the special needs trust is included in your estate for tax purposes and for potential lawsuits. If someone sues your estate after you are gone, for example, the assets in your special needs trust could be lost in such a lawsuit.

By creating an irrevocable trust, any assets you place in it will remain there solely for the benefit of the person with the disability. Even if you need some of these assets later on for your own care, you cannot take them out. Any assets placed in the trust cannot be touched by your creditors for debts, taxes, etc. Neither can the trust be touched by creditors of the person with the disability. As long as the trust is set up properly, it is completely separate from your estate, having a separate entity and its own tax number.

Whether to choose a revocable or irrevocable trust can depend on the age of the parents. For younger parents, the answer may be a revocable trust. For older parents, the irrevocable trust may be the only option. Your attorney, in consultation with your financial planner, is probably the best resource in making this determination. It is important, however, to create a current letter of intent, which will help your trustee interpret the "legalese" of either the revocable or irrevocable trust, in light of your hopes and desires for the future of the person with the disability.

Trustee: The Manager of Resources

It is one thing to leave resources to a trust, and it is quite another to manage them in a way to last the lifetime of the person with the disability. Every trust must have a trustee, someone who will manage the trust's assets. As most special needs trusts are

established to provide supplementary assistance, they generally are quite small by bank standards. Ideally, it would be nice to have a local bank manage the trust resources, while taking a personal interest in the person with the disability; sadly, very few banks are willing to manage cash assets under \$150,000 to \$200,000 or become as involved in the person's life as you would wish.

In the case of a living trust where there are sufficient funds and relatives, the family usually nominates future or successor trustees to manage the trust after the parents die or go into a nursing home. Families may even nominate a group of people to serve as joint trustees—several relatives, perhaps—who administer the trust together. An advocacy or disability organization also should be listed as the last successor trustee because it is possible that the human successor trustees will die before the person with the disability. In the event that the human successor trustees are unable to serve, the advocacy or disability organization may take on the responsibility, or be able to recommend someone in their group who could do so. Of course, discussing this with the disability or advocacy group to obtain consent first, before listing the organization as a future trustee, is a good idea.

Financial Planning: Funding a Special Needs Trust

As families undergo estate planning for their loved ones, they tend to think of it as a legal issue only. However, a lawyer can only establish the trust. Someone has to find the funds to put into the trust and make sure there are sufficient funds to last the lifetime of the person with the disability. That is where a financial planner comes in.

Financial planners sometimes have the reputation of trying to sell investments and insurance through high-pressure techniques. And while the financial planner may very well use various financial products to fund the trust, the more reputable ones realize that most families have limited resources. Therefore, the planner's primary job is to help the family see what resources are available and then re-allocate them, so that the future funding of the trust will be realistic.

As with attorneys, there are very few financial planners who have any experience with planning for the future of a person with disabilities. Most are trained to look at the overall family estate and provide as many dollars as possible, while looking out for potential problems. When they realize that there is a person with a disability involved, they may assume that the person will need extra help, and direct more dollars to the person with a disability, without understanding the consequences this might have in terms of the person's government benefits.

An experienced financial planner will examine your letter of intent and run a detailed financial analysis based on the

Resources to Fund a Special Needs Trust

- 1) **Standard government benefits.** These can make the foundation for the future.
- 2) **Savings.** No matter how much money the family will have to leave for the trust, the government benefits will have to be provided for the person with the disability. Regular savings and grants are essential to meet the person with the disability's supplementary needs in the future.
- 3) **Family assistance.** Family members may wish to provide special care and services and supplemental assistance during the child's life.
- 4) **Parents' estate.** Parents may leave a portion of their net estate to the trust.
- 5) **Inheritances.** Relatives or friends who have expressed an interest in providing for the person with the disability should be given instructions and assistance on how to leave a gift to the trust.
- 6) **Property.** Some families want their loved one to live in the same house. The house can be placed in the trust and managed by a trustee for the benefit of the person.
- 7) **Investments.** Certificates of deposit, IRAs, REITs, etc., can be directed to the trust.
- 8) **Military benefits.** Some families have elected a duty or benefit option (DBO) to the person with the disability. All veterans have some form of financial package that usually varies according to the status of the veteran's resources, which will supplement the military benefits.
- 9) **Insurance.** For the average family, life insurance may be the only way that someone can leave a substantial amount by making small financial decisions. It also covers the very expensive methods of funding a trust. While the above items are listed, it is not intended to be an exhaustive list of the resources available. A professional planner or lawyer will guarantee future needs.
- 10) **Other resources.** Many families have a special savings plan to help a child with a disability. It will help fund a child's education and provide for the child's future needs.

future costs of supplementary items and advocacy. The planner then will look at the many different resources available to fund the trust, now and in the future.

Most families are surprised to learn that they do in fact have a variety of resources within their reach that can be directed to the special needs trust, including:

As families examine ways to fund the trust, they need to keep in mind something very important: Do not forget the other brothers and sisters. Sometimes families assume that, while they must pay for the services of a bank trustee and a guardian/advocate, relatives who take on these responsibilities should do so for free, because that is what families do. While the siblings may be pillars of love and understanding when it comes to their brother or sister

with a disability, they probably have seen a great deal of your time and energy spent in the disability arena. They should not be left out at the end.

With proper legal and financial planning, a family can guarantee that the person with the disability will enjoy a comfortable lifestyle after the parents are gone.

Richard W. Fee, associate professor, is the director of the Deaf and Hard of Hearing Teacher Education at MacMurray College, Jacksonville, Ill., and executive director of the National Institute on Life Planning for Persons with Disabilities. He has 30 years experience as a teacher and administrator in special education.

Planning for the Future

A 1996 survey conducted by the ICR Survey Research Group showed that at least one individual in 20 percent of U.S. households is a caregiver - either part-time or full-time. Planning for the future of people with disabilities is something they and their families/caregivers must tackle - and the sooner the better.

Whether the person with special needs is 4 or 40 years old, it is imperative that families create a plan. Despite the growing number of persons with developmental disabilities in this country, less than 20 percent of families have done any planning.

Whether people with disabilities function entirely on their own or need assistance, a written directive can provide instruction for daily care, as well as unexpected and sudden contingencies.

- How would these individuals like to be bathed and dressed?
- What music do they enjoy, and when do they want to listen?
- Do they have special dietary needs and requirements?
- Who monitors their medication?
- What activities do they enjoy?
- How can they live with dignity, quality, self-esteem, and security?

Family members/caregivers should discuss information regarding the needs and desires of people with disabilities and compose a directive document addressing the lifestyle, financial, legal, and government-benefit issues.

Most people realize they need to plan and want to do something, but they fail for a variety of reasons. Some believe the task is overwhelming - they don't know where to find qualified professionals who understand their needs and how to resolve their concerns. And, too, the cost of professional services can be prohibitive. Families are also concerned with privacy issues. How do they overcome these obstacles and begin planning for the future?

As families begin their plan, they should first identify the people that can assist in the planning process. This should include, when possible, the family, the person with a disability, an attorney, a financial advisor, caseworkers, medical practitioners, teachers, therapists, anyone involved in providing services, and a lifetime assistance planner to act as a "team" advisor to make sure that all parts of the plan are coordinated and complete.

The planning process that financial planner Barton Stevens, ChLAP, recommends addresses four key issues affecting the life of the person with special needs. They are:

1. Lifestyle
2. Legal
3. Financial
4. Government Benefits

Lifestyle. Lifestyle planning is where the family records what they want for the future of their loved one. This information is recorded in a document called the "Letter of Intent." Although not a legal document, it is as important as a Will and a Special Needs Trust. Lifestyle issues require decisions regarding where the person will live, continued education programs, employment, social activities, religious affiliation, medical care, behavior management, advocacy and/or guardianship, trustees, and final arrangements.

In addition, detailed instructions are provided for assisting the person with the typical activities of daily living such as bathing, dressing, feeding, and toileting. Perhaps the person has a special way of communicating that only the immediate family knows and understands. It is important that this information be included. Rather than write hundreds or thousands of words describing how to do these things, it is recommended that families videotape them performing the activities of daily living, communicating, and in different social settings such as the home, school, a day care center, and so on.

Imagine how much easier and less traumatic it will be for the person with special needs and the care providers if

they have detailed instructions immediately available to them rather than having to figure things out on their own. What could take weeks or months to adjust to could be shortened to a few days. The ultimate goal is to make the transition from parental care to independent living, residency in a group home, or moving in with other family members as easy as possible, bearing in mind the comfort and security of the person.

Legal. Legal planning provides for the family to state their wishes as to the distribution of their assets and appointing executors to settle their estate. In conjunction with this, a trust is usually executed to provide professional money management, trustees, guardians, maintain government benefits, and protect the assets left for the individual.

The "Irrevocable" Special Needs Trust is the most commonly used document to provide, supplemental funds for the exclusive benefit of the person with a disability. The assets are not in the name of the person, so they will not cause the loss of SSI (Supplemental Security Income) health care benefits. This Trust has proven invaluable to families regardless of the size of their estate or the amount of assets they are leaving.

Financial. Financial planning is used to determine the supplemental needs of the person. First, a monthly budget is established based on today's needs while projecting for the future. Then, by using a reasonable rate of return on principal, the family identifies how much money is needed to fund the trust. In addition, the life expectancy of the person must be considered and then the need projected into the future using an inflation factor.

Once this is done, the family must now identify the resources to be used to fund the trust. They may include stocks, mutual funds, IRAs, 401(k)s, real estate, your home, life insurance, etc. Professional management for investing the assets may be done by the Trustee, or the Trustee may hire advisors.

Government Benefits. Government entitlements play a key role in the lives of many persons with special needs by providing cash and health care benefits under SSI (Supplemental Security Income), SSDI (Social Security Disability Insurance), Medicaid, and Medicare. A basic understanding of federal and state entitlement programs is essential in order to be sure that the person gets all that they are qualified to receive, and that assets received from family members through gifts, inheritance, and litigation do not result in the disqualification and termination of government benefits or the government claiming reimbursement for benefits provided from assets received by the person.

It should be clear that each of these issues is interrelated and requires they be coordinated in the planning process. Those persons who provide advice in one particular area should be made cognizant of what others are doing. This emphasizes the importance of an organized plan.

The result of a comprehensive plan should be that it: provides lifetime supervision and care; maintains government benefits; provides supplementary funds to help ensure a comfortable lifestyle; provides management of funds; provides dignified final arrangements; and avoids family conflict.

The 10-Step Process

In order to prepare a plan in a simple step-by-step procedure without feeling overwhelmed by the process, Barton Stevens recommends that families commit to know the 10 life planning steps. If these steps are followed, the family will create a directive that addresses the lifestyle and care needs of the person.

There are 10 steps you follow to help you create a directive that addresses the lifestyles and care needs of people with disabilities. The information recorded depends on the type and severity of the disability.

1. **Prepare a life plan.** Decide what you want regarding residential needs, employment, education, social activities, medical and dental care, religion, and final arrangements.
2. **Write informational and instructional directives.** Put your hopes and desires in a written document. Include information regarding care providers and assistants, attending physicians, dentists, medicine, functioning abilities, types of activities enjoyed, daily living skills, and rights and values. Make a videotape during daily activities such as bathing, dressing, eating, and recreation. A commentary accompanying the video is also useful.

3. **Decide on a type of supervision.** Guardianship and conservatorship are legal appointments requiring court-ordered mandates. Individuals or institutions manage the estate of people judged incapable (not necessarily incompetent) of caring for their own affairs. Guardians and conservators are also responsible for the care and decisions made on behalf of people who are unable to care for themselves. In some states, guardians assist people and conservators manage the estate of individuals. Many parents who have kids with disabilities do not realize that when their children reach 18, adults may no longer have legal authority. Choose conservators/guardians for today and tomorrow. Select capable individuals in the event you become unable to make decisions in the future.
4. **Determine the cost.** Make a list of current and anticipated monthly expenses. When you have established this amount, decide on a reasonable return on your investments, and calculate how much will be needed to provide enough funds to support his or her lifestyle. Don't forget to include disability income, Social Security, etc.
5. **Find resources.** Possible resources to fund your plan include government benefits, family assistance, inheritances, savings, life insurance, and investments.
6. **Prepare legal documents.** Choose a qualified attorney to assist in preparing wills, trusts, power of attorney, guardianship, living will, etc.
7. **Consider a "Special Needs Trust."** A Special Needs Trust holds assets for the benefit of people with disabilities and uses the income to provide for their supplemental needs. If drafted properly, assets are not considered income, so people do not jeopardize their Supplemental Security Income or Medicaid. And, too, they don't have to repay Medicaid for services received. Appoint a trustee and successor trustees (individuals or corporate entities, such as banks).
8. **Use a life-plan binder.** Place all documents in a single binder and notify caregivers/family where they can find it.
9. **Hold a meeting.** Give copies of relevant documents and instructions to family/caregivers. Review everyone's responsibilities.
10. **Review your plan.** At least once a year, review and update the plan. Modify legal documents as necessary.

Once you have decided to prepare a plan, find someone to help you or hire a professional planner. Referral sources are available through governmental agencies, organizations, or local support groups. "Who will care when you are no longer there?" is an overwhelming concern people with disabilities and their families must address. Solutions are available. The next step is up to you.

Note: The previous section was provided by Barton Y. Stevens, ChLAP, founder and Executive Director of Life Planning Services in Phoenix, AZ, who has been providing estate and financial planning services since 1972.

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- [Safety in the Home](#)
- [Sibling Issues](#)
- [Life After High School](#)
- **[Planning for the Future](#)**
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Planning for Your Child's Future Who Will Care When You're Not There?

By Barton Stevens

Michael, 12, has autism. Every day his mother waits eagerly for the van that brings him home from the local school's special education program. She has been his only caregiver since he was born, and she worries about the future. "Everything is in a holding pattern now," she says, "but what will happen to Michael when I am elderly and can no longer take care of him? And, God forbid, if I die tomorrow, what kind of life will he have?"

A 1996 survey conducted by the ICR Survey Research Group showed that at least one individual in 20 percent of U.S. households is a caregiver—either part-time or full-time. Planning for the future of people with disabilities is something they and their families/caregivers must tackle—and the sooner the better.

Whether the person with special needs is 4 or 40 years old, it is imperative that families create a plan. According to the U.S. Census of 1991-92, there are now over 10 million persons with developmental disabilities. Yet, less than 20 percent of families have done any planning.

Whether people with disabilities function entirely on their own or need assistance, a written directive can provide instruction for daily care, as well as unexpected and sudden contingencies. How would these individuals like to be bathed and dressed? What music do they enjoy, and when do they want to listen? Do they have special dietary needs and requirements? Who monitors their medication? What activities do they enjoy? How can they live with dignity, quality, self-esteem, and security?

Family members/caregivers should discuss information regarding the needs and desires of people with disabilities and compose a directive document addressing the lifestyle, financial, legal, and government-benefit issues.

Most people realize they need to plan and *want* to do something, but they fail for a variety of reasons. Some believe the task is overwhelming—they don't know where to find qualified professionals who understand their needs and how to resolve their concerns. And, too, the cost of professional services can be prohibitive. Families are also con-

cerned with privacy issues. How do they overcome these obstacles and begin planning for the future?

As families begin their plan they should first identify the people that can assist in the planning process. This should include, when possible, the family, the person with a disability, an attorney, a financial advisor, caseworkers, medical practitioners, teachers, therapists, anyone involved in providing services, and a lifetime assistance planner to act as a "team" advisor to make sure that all parts of the plan are coordinated and complete.

The planning process I recommend addresses four key issues affecting the life of the person with special needs. They are **Lifestyle, Legal, Financial, and Government Benefits.**

Lifestyle

Lifestyle planning is where the family records what they want for the future of their loved one. This information is recorded in a document called the "Letter of Intent." Although not a legal document, it is as important as a Will and a Special Needs Trust. Lifestyle issues require decisions regarding where the person will live, continued education programs, employment, social activities, religious affiliation, medical care, behavior management, advocacy and/or guardianship, trustees, and final arrangements.

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Imagine how much easier and less traumatic it will be for the person with special needs and the care providers if they have detailed instructions immediately available to them rather than having to figure things out on their

own. What could take weeks or months to adjust to could be shortened to a few days. The ultimate goal is to make the transition from parental care to independent living, residency in a group home, or moving in with other family members as easy as possible, bearing in mind the comfort and security of the person.

Legal

Legal planning provides for the family to state their wishes as to the distribution of their assets and appointing executors to settle their estate. In conjunction with this, a trust is usually executed to provide professional money management, trustees, guardians, maintain government benefits, and protect the assets left for the individual.

The "Irrevocable" Special Needs Trust is the most commonly used document to provide, supplemental funds for the exclusive benefit of the person with a disability. The assets are not in the name of the person, so they will not cause the loss of SSI (Supplemental Security Income) health care benefits. This Trust has proven invaluable to families regardless of the size of their estate or the amount of assets they are leaving.

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Government Benefits

Government entitlements play a key role in the lives of many persons with special needs by providing cash and health care benefits under SSI (Supplemental Security Income), SSDI

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QUIZ

Do You Need a Plan?

Take this quiz and find out. If you answer no to any of the following questions, it's time to get organized.

- Is there a written plan to let others know what is wanted in the future?
- Has anyone been asked to serve as advocate or guardian?
- Do you understand all available government benefit programs for basic care and supervision?
- Have you set aside any additional funds to ensure a comfortable, quality lifestyle ensuring dignity and self-esteem?
- Have you prepared written instructions for your final arrangements?
- Do you have a current will?
- Do you have a special-needs trust to manage current and future resources?
- Have you met with relatives and friends to let them know about your plan?
- Have you reviewed your plan in the last year?

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(Social Security Disability Insurance), Medicaid, and Medicare. A basic understanding of federal and state entitlement programs is essential in order to be sure that the person gets all that they are qualified to receive, and that assets received from family members through gifts, inheritance, and litigation do not result in the disqualification and termination of government benefits or the government claiming reimbursement for benefits provided from assets received by the person.

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include disability income, Social Security, etc.

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At least once a year, review and update the plan. Modify legal documents as necessary.

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"Who will care when you are no longer there?" is an overwhelming concern people with disabilities and their families must address. Solutions are available. The next step is up to you.

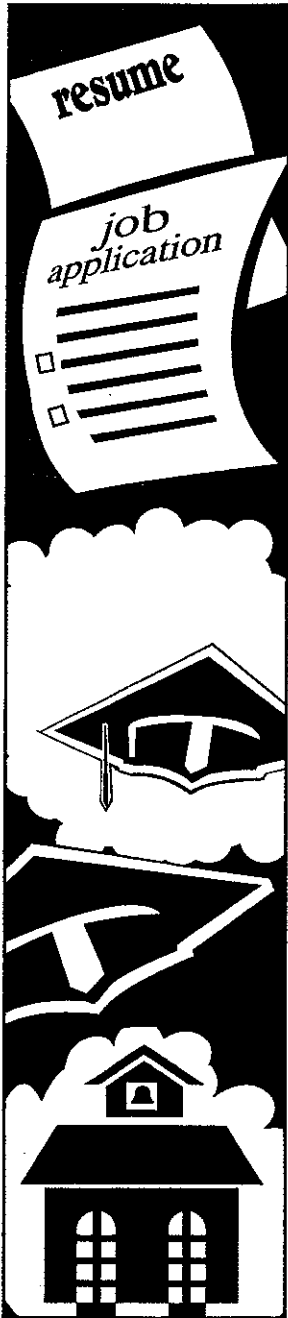
For a copy of the ASA's "Federal Programs for Adults with Autism" package, which is free to members, contact the ASA at 800-328-8476 ext. 150.)

Barton Y. Stevens, ChLAP, is founder and Executive Director of Life Planning Services in Phoenix, AZ, and has been providing estate and financial planning services since 1972.

For more information, you may visit the Life Planning Services web site

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Building a Future Requires Vision, Planning



What are my dreams and visions for the future? What about middle and high school? What will I be doing after high school? What do I want to be doing and where will I live as an adult?

Finding possible answers to these questions and choosing among them are important endeavors for all students. For students with disabilities, envisioning possible futures and choosing among them require complex considerations and careful planning. Plans and choices made during the school years are critical to a student's later success in life. Yet, all too often, what is learned in high school does not support students' visions for their future.

Terri McLaughlin, Federation Transition Specialist, encourages parents to work with schools to develop meaningful transition plans for their youth with disabilities. She compares developing a good transition plan to creating a structure or building a home: "You begin each process by dreaming. With the help of a good architect, a blueprint is developed, showing how the structure will reflect the lifestyle of the inhabitants. Next, you need a builder to ensure that each piece of the building process happens in the right order and on schedule. Individual effort and expertise and the careful collaboration of many committed people result in a structure that truly reflects the owner's vision."

McLaughlin concludes, "Transition planning is a collaborative process that is ongoing, student-driven, and outcome-based. Like a home, the outcome of a good transition plan is also a dwelling place, one made up of a collection of life experiences that reflect a person's hopes and dreams and that empowers the person to live them."

Legal Requirements for Transition

As long as a student is eligible for special education services, federal and state laws require that transition needs and services be addressed in the student's IEP. *At age 14 years* or younger, IEPs must contain a "statement of the transition service needs of the student." Parents and students can use this requirement as an opportunity to begin developing a transition plan with school personnel. In fact, from age 14 on, the IEP meeting is often referred to as an IEP/ITP (for Individual Transition Plan) meeting. This IEP statement should begin with a vision of the future the student desires. The service needs identified should focus on the student's

course(s) of study and be integrated into the IEP.

At age 16, or younger if appropriate, the school should begin to include transition services in a wide range of areas. "Transition services" means a coordinated set of activities designed to promote movement from school to

such post-school activities as, for example, college, employment, vocational training, and independent living. Transition services the school should provide may include, but are not limited to: instruction, community experiences, the development of employment and other post-school living objectives, and when appropriate, the acquisition of daily-living skills and vocational assessment.

The statements of transition needs and services, which are the basis of a transition plan, identify what students need to experience, learn, and know to be prepared for a meaningful and rewarding adult life. For the eight years from ages 14 to 22, the *statements of transition needs and services are a formal, required part of the IEP*. As one grows and develops, so does one's vision for the future. As priorities, preferences, and dreams emerge and evolve, IEP/ITPs should be updated annually to reflect new priorities among the many components of an effective transition plan.

The Federation for Children with Special Needs, in collaboration with the Massachusetts Department of Education, is presenting transition workshops during the 1999-2000 school year in a community near you. These comprehensive workshops will guide parents and professionals as they develop IEPs with transition services for students with disabilities.

See page 13 or check out our website at www.fcsn.org to see an updated list of training workshops, and mark your calendar now! For more information, contact Terri McLaughlin at the Federation's Boston office; 617-236-7210 or 800-331-0688, ext.185.

SSI Rule Changes at 18

Another important consideration in transition is the student's status concerning Supplemental Security Income (SSI). When a student turns 18, the following changes to eligibility rules apply:

For new applicants:

- Once students turn 18, their financial eligibility is no longer based on family resources, but is based solely on the student's income, resources, and living situation (even if the student continues to live at home).

For students who have been eligible for SSI and must go through redetermination:

- There must be a severe impairment that limits the ability to do basic work activity.
- The individual must be currently disabled (determined by whether they are working and earning over \$700 a month).

For more information, check out ruralinstitute.wmt.edu/rises or call Maria Christina Vlaxidis, Institute for Community Inclusion, at 617-355-4673.

The Impact of Personal Futures Planning on Families

by Angela Novak Amado

Personal Futures Planning is an individualized, structured, possibility-based approach to life planning. The individual plan represents a vision for a more desirable future, developed by a group of people who care about the individual and are willing to assist in making the plan become a reality.

The process starts with a focus person, a group of people who care about the focus person, and a group facilitator. Large sheets of paper on the wall are covered with colorful pictures and statements. The first meeting, a Personal Profile, looks at a person's history, relationships, strengths, and gifts. In the second meeting, the group develops a dream or vision for a desirable future. People make commitments to certain actions to help bring the dream into reality. Then, the group continues to come together to share successes and failures and to continue to move forward.

Personal Futures Planning was developed by Beth Mount and John O'Brien, and has been used for more than 10 years in many different states. It can be used with any person of any age. It is often used to discover what's possible for people when looking from the perspective of the person's capacities rather than the traditional deficit-based planning approach, and to empower people who care. Persons with disabilities, service providers, case managers, and families, have all reported being profoundly impacted by the process. They can see people in new ways, understand people much differently, and be more inspired to realize much different dreams and visions for the person than what occurs in traditional planning processes.

The Minnesota Governor's Planning Council on Developmental Disabilities has sponsored three years of training in Minnesota on Personal Futures Planning. More than 200 people have received plans in those years, and many families have also been impacted. Some examples of the kind of differences the process makes for families and for individuals with disabilities are the following:

- **Transitions.** Personal Futures Planning is often used at different transition points, such as from early childhood to regular school programs and from school to adult services. It is also used for transition to new services, such as group home to apartment living and sheltered to supported employment. One example of using Futures Planning for transitions is Emily's parents and early childhood staff, who used the process to discover that it was possible for her to go to regular kindergarten. At the planning meeting, Emily's mother said: "We had hopes for her. But we never told people those hopes because we didn't think they could happen." Emily now attends kindergarten in a district that has never before served children with her severity of disability in regular kindergarten.

- **Services.** The Futures Planning process can often help clarify what the best situations for people could be. For example, Gary's family could not care for both Gary and his sister at home, and his mother would not hear of him moving to a group home. The planning group helped find a foster couple who lived near Gary's family and went to the same church. Gary's mother is now able to feel good about him living away from home.
- **How the Person is Seen.** In the Futures Planning groups, families and other group members often come to see the person in new ways, such as viewing them as more like other people and more capable. For example, a woman who had been living in a locked unit at a regional treatment center was thought to be helpless or dangerous; however, when she was pouring coffee and socializing at her planning meeting, family and other group members had their anxieties eased. They helped her move out of the center and back to her hometown.
- **Empowerment.** Through Personal Futures Planning, families can be empowered in obtaining support and in facing sometimes scary decisions and futures. For instance, Gordon's mother was empowered to move from just complaining to writing and getting others to write letters requesting more respite care.
- **Being Involved.** Often, the Futures Planning process has enabled family members to become involved again. The focus is on capacity and gifts, and the real interest is in a person as a human being, not just a "client" or "special education student". Through the process, group members often get excited about inviting family back into people's lives. For example, Pat's family members have been amazed to discover that the person they thought was "a vegetable" is very capable, and have been thrilled to reconnect with him as part of their family.

Personal Futures Planning as a process has brought people together who have traditionally been adversarial or focused on the service system. It has allowed them to see and care about others as real human beings. Through the process many individuals with disabilities and their families have been able to express wishes and dreams, and to have those dreams come true.

Angela Novak Amado is the Executive Director of the Human Services Research and Development Center, 357 Oneida Street, St. Paul, MN 55102. For further information on Personal Futures Planning contact the center, or see the Resource list on page 19 of IMPACT.