HOME CONTROL AND OWNERSHIP:

REAL HOMES FOR REAL PEOPLE

BY:

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TABLE OF CONTENTS

INTRODUCTION

This information manual on home control and home ownership for persons with disabilities has been prepared to provide individuals and families with information to assist them in their effort to secure control over their housing. The manual provides information about government benefits, trusts, estate planning, and financing strategies for obtaining and keeping a home. The information presented is necessarily general in nature; there is no one set path to be charted. Nonetheless, considerations will be explored and some solutions will be offered. While each situation is as unique as the individual involved, it is prudent to explore all options, including those which may not necessarily seem to be applicable to persons with disabilities.

While many persons with disabilities live at home with their families by choice, others do so because they are unaware of the options available to them. This manual will evaluate the major barriers to independent living faced by persons with disabilities. It will also discuss how individuals and families can overcome these barriers. The two most common obstacles are a lack of finances and community based support services. Due to a financial reliance on subsistence level government benefits, such as Supplemental Security Income (SSI) or Social Security Disability Income (SSDI), people with disabilities are often unable to afford a home of their own. Even when individuals with disabilities have families who are able to assist them with the purchase of a home, they are often unable to provide the support that makes it possible for the individual to live independently.

In recent years, several factors which bolster the efforts of persons with disabilities in overcoming these barriers have made planning for home control a much more realistic option.

These events include:

- Growth in supervised apartment programs;
- Development of the Plan to Achieve Self-Support (PASS) provision by the Social Security Administration (SSA);
- Changes in U.S. Department of Housing and Urban Development (HUD) policies;
- Tremendous growth in and availability of technological devices and equipment, enabling persons who were previously unable to live alone to now do so;
- Growing knowledge of special needs trusts by attorneys;
- Changes in federal Medicaid regulations which enable parents of persons with disabilities to establish trusts;

- Changing perception and attitude towards persons with disabilities and a recognition of the ability of these individuals to grow and develop throughout their lifetime;

- Civil rights movements that recognize that persons with disabilities are entitled to an equal opportunity to enjoy life, including the right to live in the community and the ability to control their own environment;

- *Olmstead v. L.C.*, 527 U.S. 581 (1999) – Supreme Court ruling that requires states to eliminate unnecessary segregation of person with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs;

- Passage of the ABLE Act in December, 2014 providing families an opportunity to save funds for disability-related expenses above and beyond the SSI resource limit; and

- Centers for Medicare and Medicaid Services (CMS) published final rules for Home and Community Based Services, mandating that Medicaid waivers serve people in the community.

The information provided here will empower persons with disabilities and their families to explore alternatives to the traditional "provider-based" service delivery system. Estate planning and the preservation of eligibility for government benefits can be extremely complicated subjects. Still, families should use information about these issues to better inform themselves of the choices available to them.

Please note that this manual is not intended as specific legal advice. When planning for the future, families should retain the services of an attorney, a financial planner and other resource persons as may be appropriate, who are knowledgeable about the needs of persons with disabilities.

In referencing the individual with a disability, the authors have used "he" and "his" in lieu of "he or she" and "his or her" for fluency and ease of reading only, not to identify disability with gender.

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CHAPTER 1:

WHERE WE WERE – A HISTORICAL OVERVIEW OF RESIDENTIAL OPTIONS AVAILABLE TO PERSONS WITH DISABILITIES

Until recently, individuals with disabilities had a limited selection of housing options when their parents died or were unable to care for them. Some individuals were fortunate enough to have another family member who was able to continue to care for them. However, when no other family member existed who was able to provide housing and supervision, individuals were often placed in emergency respite care, admitted to a state institution or a community-based facility, or placed in a group home or nursing home. The twofold trauma caused by the loss of one's parents as well as the loss of a lifestyle was devastating. Today, with careful planning, families can avoid this kind of terrible outcome.

In the 1970's, advocates for persons with disabilities and their families began organizing to increase alternative residential options in less restrictive surroundings. However, the number of community-based group homes failed to keep pace with the demand for less restrictive settings. While community-based options offered more freedom and interaction with others, the home-like option of a group home still failed to provide personal control over the living environment.

Persons without disabilities have the right to live in a home of their choice, with roommates of their choice, and in a neighborhood of their choice. Persons with disabilities are systematically denied these same basic liberties creating a major civil rights issue. At long last, advocates are beginning to realize that persons with disabilities have a right to enjoy equality of choice, and thus must be allowed more control of where and with whom they live.

Under traditional service delivery systems, persons with disabilities still live primarily at the will of a service provider who controls his or her housing options. While group homes are less restrictive than institutions, group homes do not allow a person with a disability the control over his or her environment. Policy makers, in considering the delivery of residential services, need to provide housing options which are the same, or are at least similar, to the options that persons who are not disabled have access to. Acceptance of the principle—that persons with disabilities are more like us than not—changes the focus of planning for future housing options.

A person should not have to move because his or her medical needs increase or decrease. The most recent policy and program developments allow adjustments to the level of support which prevent persons from being discharged to a different home as a result of their increased or changing needs. In addition to the constant possibility of losing a home due to a change in needs, people who live in group homes also often lack personal liberty within their home. A facility, regardless of how comfortable it appears, is not a home as long as adults have to ask permission before they can invite a friend to visit, to get a snack after dinner, or to use the phone. A setting is not a home if the staff have the power to violate a person's privacy by going into his or her room at any time, looking through his or her closet, or regulating his or her leisure time. It is not unusual for people with disabilities to be required to spend all of their leisure time together, attending the same activities or events, all due to the need to maintain a proper staffing pattern.

When a person thinks of home, he or she thinks of a private place that is safe, secure and where he or she has control over the environment. Whether a person rents or owns his or her home, there is a sense of belonging and security when one can choose where and with whom to live. A home provides a personal and private space where one can relax, invite friends to stop by or just choose to be alone. Unfortunately, this freedom is often unavailable when a person lives in a group home, even when it is considered home-like.

Housing options, that enable persons with disabilities to think of their home as persons without disabilities do, are clearly the ideal. There are those who will reject this ideal as unrealistic and impossible to achieve, but the information in this manual will prove that, using the correct resources, persons with disabilities can have a home of their own. This manual is being written at a time when more and more service providers and policy makers are recognizing the need to develop policies that enable people with disabilities to have the same housing choices that the rest of us enjoy. The self-advocacy movement, civil rights legislation, and an explosion of new technology and assistive devices force us to re-examine traditional concepts about service delivery and housing options. With cautious optimism, families can look forward to many new funding options in the near future enabling persons with disabilities to live in and have control over a home of their own.

CHAPTER 2:

TAKING STEPS – PLANNING FOR THE FUTURE AND INCREASING OPPORTUNITIES FOR HOME OWNERSHIP

One of the greatest concerns to parents of persons with disabilities is what will happen to their child when they die. Persons with disabilities are often dependent upon their parents to supplement the cost of their care above and beyond any government benefits they receive. The support that persons with disabilities receive from family members in housing or supervision makes it possible for them to live in the community. In planning for the death of a primary caregiver, parents must give careful thought to how those support services will continue to be provided. Some of the most important questions to be considered are answered below.

Q. WHAT ISSUES DO FAMILIES NEED TO CONSIDER IN PLANNING FOR THE TIME WHEN THEY ARE NO LONGER ABLE TO PROVIDE SUPPORT FOR THEIR FAMILY MEMBER WITH A DISABILITY?

A. Consideration must be given to the nature and severity of the particular disabling condition of the individual, as well as his or her interests and housing preferences, along with the various local, state and federal programs available for his or her benefit

Families seldom add up the costs of the various forms of support they give to a family member with a disability. Those parents who contend that their child's financial needs are minimal often forget to add up the cash value of the many services they provide their child, such as serving as their child's advocate, service coordinator, companion, guardian, job coach, chauffeur, personal care attendant, money manager and recreation director. These services add immeasurably to the quality of their child's life. If parents die without planning for the continuation of these services, the quality of life that the person with a disability previously enjoyed is likely to be reduced substantially.

While some of the services previously provided by family can be duplicated by the government, many cannot. It is essential to determine how much it will actually cost to buy the supports and services which are not provided by the state.

It is equally important for parents to establish a special needs trust to protect their son's or daughter's inheritance. Without careful estate planning, an inheritance will jeopardize a person's eligibility for government benefits. If an inheritance disqualifies an individual from government benefits, then it will have to be spent on basic care and support, rather than serving as a supplemental source of funds. In this case, the money will likely be quickly depleted, leaving no funds to pay for those services that the government does not provide. A special needs or discretionary trust created for a person with a disability offers that person additional housing options and is a key part of future planning for families of persons with a disability.

Q. WHEN SHOULD FAMILIES BEGIN PLANNING?

A. It is never too early to start planning. An ideal time to begin planning for the future and considering housing options is when the individual is in junior high school. At this age, it is the school's duty to plan for the special education student's transition from school to adulthood and independence. By junior high, families often have a clearer picture of the supports and services that their family member will likely need. However, since we cannot predict the future, there is certainly nothing wrong with planning earlier.

Q. WHAT STEPS SHOULD FAMILIES TAKE WHEN PLANNING FOR THE FUTURE?

A. 1. Families need to become familiar with public and private, local, state and federal programs and agencies that offer supports and services to people with disabilities and their families.

2. The family must determine the preferences of the individual with a disability, as well as his or her ability to participate in decisions regarding residential options, along with future care and support.

3. The family must calculate the resources that will be needed to supplement the care and support the family member will receive from the government.

4. The family should meet with an attorney knowledgeable in this specialized area of estate planning and who understands the government benefits available to provide support and services for persons with low-incomes and/or disabilities. In order to write a will or trust document which preserves eligibility for government benefits, knowledge of the eligibility requirements for those who are in critical need of government benefits is required. In addition, the more conventional goal of minimizing estate taxes continues to be relevant since it will help maximize the inheritance of the family member with a disability.

5. The family should determine what share of the estate will be needed to meet the desires of the family member with a disability after the parents die. If that percentage is disproportionately high (meaning: if it results in disinheritance of or a reduction of an inheritance to other heirs who are not disabled), the impact should be considered. This is especially true for cases in which one of the other family members is asked to provide services. It may be possible to supplement the share left to a family member with a disability through life insurance or other planning.

6. The family should meet with a financial planner who is familiar with government programs for persons who are disabled to discuss how the family's assets can be preserved or invested to better meet the needs of the family member who is disabled.

7. If home ownership is a goal or priority, the family should meet with a knowledgeable real estate broker who is familiar with federal and state homeowner assistance programs available for persons who are low-income and/or disabled.

8. Having done careful planning, the family needs to preserve the information garnered. Much of the planning will be incorporated into crucial estate planning documents, but other equally important information should be otherwise recorded to assist those who take over when parents can no longer be the primary caregivers. A resource file of the information learned should make for a smoother transition. Many professionals have formats for a “Letter of Intent” to give parents a framework for recording essential information to be given to those who succeed them.

9. Lastly, the family must write wills which include a special needs trust. A special needs trust is a trust used to provide supplemental care, meaning care above and beyond what the beneficiary is eligible for government benefits. A properly worded and properly managed special needs trust will not jeopardize government benefits, which may, in most cases, be more valuable than an outright inheritance.

CHAPTER 3:

THE KEY COMPONENT – UNDERSTANDING GOVERNMENT BENEFITS

Few families can afford to pay for all of the support and services needed by a family member with a disability. When the primary caregiver dies, the family member with a disability is in even greater need of the basic care and support provided by the government. Therefore, knowledge of government benefits is critical. Families are often overwhelmed and intimidated by the agencies that provide services. In addition, it can be difficult to keep track of who provides what and to what extent.

It may help to understand that, conceptually, there are only three basic types of government benefits. All programs and services fit into one of these three types:

1) **Welfare Benefits**: Based on financial need; such as: SSI and Medicaid

2) **Entitlement Benefits**: Not based on financial need; such as: SSDI and Medicare

3) **Sliding-Scale Government Benefits**: Based on a person's ability to pay determined by his resources and income; such as: services available from federal and state departments of mental health and developmental disabilities and the federal and state departments of health and human services, SNAP (food stamps), Section 8 housing, Health Benefits for Workers with Disabilities; and fuel assistance

Q. WHY DO MIDDLE OR UPPER INCOME FAMILIES NEED TO BECOME FAMILIAR WITH WELFARE BENEFITS?

A. If the income of a person with a disability is limited to SSI or SSDI and, perhaps, part-time wages, they may be eligible for many of the programs that are available for low-income families. By becoming familiar with low-income and welfare programs, families can often obtain more services for the family member with a disability than if they simply apply for services available through agencies that serve persons with disabilities.

Q. HOW DOES THE FEDERAL GOVERNMENT DEFINE "DISABILITY?"

A. "Disability," as defined by Social Security, is the inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months. Social Security strictly applies this definition.

Q. *HOW DOES A PERSON WITH A DISABILITY BECOME ENTITLED TO SSDI OR MEDICARE?*

A. There are two ways that a person can become entitled to SSDI or Medicare. A person can be eligible for SSDI either through his own work record or under the work record of his parents. These programs are referred to as "entitlement programs" because the recipient is entitled to receive benefits from them based on the money paid into them.

If a person has worked and paid into the Social Security system, he will become eligible if, due to a mental or physical disability, he is no longer able to work. How much money the person receives under SSDI depends on how long a person worked and how much money the person made while working. After two years of receiving SSDI, a disabled individual will also receive Medicare coverage. Medicare is a federal health insurance program that is paid for with contributions into the Social Security trust system.

Q. *CAN A PERSON WITH A DISABILITY BE ELIGIBLE FOR SSDI BENEFITS IF HE NEVER PAID INTO THE SOCIAL SECURITY SYSTEM?*

A. Yes, the individual may still be eligible for SSDI benefits through Childhood Disability Benefits (CDB) if the following conditions apply:

- Disabled prior to their 22nd birthday
- Unable to engage in "substantial gainful activity" due to a physical or mental impairment
- Remained single or has married another person who is a DAC
- One of his parents died, retired or became disabled and is collecting SSA benefits
- Deceased, retired or disabled parent paid into Social Security during his lifetime

Q. *HOW WILL AN INHERITANCE AFFECT A PERSON'S ELIGIBILITY FOR SSDI OR MEDICARE?*

A. An individual's eligibility for SSDI or Medicare will not be affected by an inheritance, nor by the amount of money he has in the bank. SSDI and Medicare eligibility is based upon an individual's inability to be gainfully employed and whether or not the individual, or his parent(s), have paid into Social Security. SSDI and Medicare are also not affected by unearned income, so if an inheritance is invested and pays a monthly dividend income check to the person with a disability, he will still be eligible. Please note, however, that it is seldom a good idea to leave a direct inheritance for a person who is developmentally disabled. An inheritance may trigger the need for a guardian of the estate which is a costly and sometimes an intrusive way of protecting a person's assets. Even if no guardianship is warranted, the person with a disability may still lack the sophistication to appropriately handle an inheritance or an income from investments.

Q. WHAT HAPPENS IF A DAC MARRIES?

A. If an individual marries another who is also receiving benefits as a DAC, benefits will continue. If he marries a person who is not entitled to DAC benefits, the individual will lose his eligibility for SSDI and Medicare benefits.

Q. ARE THERE OTHER ENTITLEMENT BENEFITS BESIDES SSDI AND MEDICARE?

A. Yes. If an individual with a disability or either parent of a DAC paid into other retirement plans such as state workers, teachers, firemen or policemen retirement programs, he may be eligible for additional benefits. Parents should contact the personnel department of the company or entity they work for to determine if their child is eligible for these benefits

Q. WHAT IS THE DIFFERENCE BETWEEN SSDI AND SSI?

A. SSDI is a Social Security insurance program that provides financial assistance for workers and for some of their dependents if the worker has paid into the Social Security trust fund system.

SSI is a welfare program available for needy or low-income people who are elderly, blind or disabled. A SSI recipient is not required to have worked or paid into the Social Security system. A person with a disability must meet an income and assets threshold in order to be eligible.

Both programs require that a person be incapable of substantial gainful activity. However, only SSI looks at how much money or other assets a person has in determining eligibility.

Q. WHAT ARE THE ELIGIBILITY REQUIREMENTS FOR SSI BENEFITS?

A. An individual's eligibility for SSI benefits is based on several factors, including age, citizenship and residency, type of disability, income, and resources. The basic requirements for eligibility are listed below. A comprehensive description of the standards and criteria for eligibility can be obtained from the United States Social Security Administration or a Social Security Office in your state. Some states have stricter requirements than the federal eligibility criteria. It is important you check with the Social Security Office in your state to determine if stricter eligibility requirements apply.

SSI ASSET ELIGIBILITY REQUIREMENTS

1. An individual can have up to $2,000 in assets, including cash, stocks, and bonds or mutual funds which can be converted into cash.

2. Life insurance with a face value of $1,500 does not count for SSI. If the life insurance has a face value greater than $1,500, then the cash value will be counted as an asset and included in the $2,000 limitation.

3. A burial plot for the individual and his immediate family does not count for SSI.

4. A prepaid funeral plan for the individual and his spouse, each valued at $1,500 or less.

5. Household goods and personal effects are not counted for SSI.

6. A home, regardless of its value if the individual lives there, is not counted for SSI.

7. A vehicle, if it is needed for transportation for the individual or a member of his household is not counted for SSI.

8. Equipment needed due to an individual's handicapping condition is not counted for SSI.

9. Tools required by the person's trade are not counted for SSI.

10. Retroactive SSI or Social Security benefits for up to nine months after receipt are not counted for SSI.

11. Grants, scholarships, fellowships, or gifts set aside to pay educational expenses for nine months after receipt are not counted for SSI.

12. Up to $100,000 in an ABLE Account.∗

Q. IS A PERSON WITH A DISABILITY ELIGIBLE FOR SSI IF HIS PARENTS ARE NOT POOR?

A. Up until the age of 18, the assets of the parents are counted as being the assets of the child with a disability. In order for the minor child to be eligible for SSI, his parents must be low-income.

Once a person turns 18 years old, the parents' assets are no longer counted. A person from a very wealthy family can be eligible for SSI as long as he does not have money or assets in his own name that exceed the permissible limits.

∗ ABLE Accounts, which are tax-sheltered savings accounts, have a maximum annual contribution of $14,000 and can be used for disability-related expenses for education, medical and dental care, job training and transportation, among other things. As of this writing, the only states to have passed and implemented the legislation and regulations for ABLE accounts are Ohio, Nebraska, Tennessee, and Florida. Many states have passed legislation, but have not yet implemented it. Current information on the status of state ABLE account legislation can be located at: http://www.ablenrc.org/state-review. See also the POMS regulations of ABLE accounts at: https://secure.ssa.gov/apps10/poms.nsf/lnx/0501130740.

Q. WHAT IS THE DIFFERENCE BETWEEN MEDICARE AND MEDICAID?

A. Medicare is a health insurance program funded by the Social Security Act. Medicare, like SSDI, is funded through payroll tax contributions into the Social Security trust system.

Medicaid is a health insurance program as well, but it does not require that a person has paid into the Social Security system in order to be eligible. Medicaid is a health insurance program for persons who are disabled and poor.

In thirty-two states and the District of Columbia, the SSI application is also the Medicaid application. Alaska, Idaho, Kansas, Nebraska, Nevada, Oregon, Utah and the Northern Mariana Islands use the same rules to decide eligibility for Medicaid as SSI, but individuals must file a separate application. Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma and Virginia use their own rules to decide eligibility, and, therefore, require a separate application for Medicaid.

Q. CAN A PERSON BE ELIGIBLE FOR BOTH MEDICARE AND MEDICAID?

A. Yes. If a person is eligible for Medicare either through his own work record or as a DAC and he meets the income and asset requirements of Medicaid, he can receive Medicaid in addition to Medicare.

Q. CAN A PERSON RECEIVE MEDICAID IF HE IS ALSO COVERED BY A PRIVATE HEALTH INSURANCE POLICY?

A. Yes. Many people incorrectly believe that private health insurance coverage results in ineligibility for Medicaid. If a person meets an income and asset requirement, he is still eligible for Medicaid. However, Medicaid is always the payer of last resort. That is, Medicaid will pay the bill only if the private insurance will not. Therefore, Medicaid is helpful in paying co-payments on private insurance or on deductible charges.

Q. IF A PERSON WITH A DISABILITY HAS PRIVATE HEALTH INSURANCE, DOES THE INDIVIDUAL STILL NEED MEDICAID?

A. Yes, definitely. Many families do not fully understand the significance of Medicaid. While private health insurance is generally superior in many ways to Medicaid, most insurance policies will not cover the cost of residential services that are not medically needed. It is critical that a person retain his eligibility for Medicaid because many community-based services are only available to persons who are "Medicaid eligible." Under the Medicaid Funded Home and Community-Based Waiver Program, a number of support services are available to persons with disabilities who are living in the community. Families need to remember that Medicaid is a public assistance program for people who have limited incomes. In order to be eligible, the person with a disability must have income and assets below the poverty level. Persons who qualify for Medicaid can receive support and services that make home ownership and control more attainable than it is for those who are not Medicaid eligible.

Q. ARE THERE OTHER WELFARE BENEFITS AVAILABLE TO HELP PERSONS WITH DISABILITIES?

A. Yes, in addition to SSI and Medicaid, if a person has a disability and his assets fall below a certain level, he may be eligible for SNAP (food stamps), Section 8 housing subsidies, low interest housing loans, and fuel assistance. These benefits, when coupled with private resources provided by a special needs trust, are often enough to enable a person with a disability to live in their own home.

Q. HOW MUCH MONEY AND WHAT OTHER ASSETS CAN A PERSON HAVE AND STILL QUALIFY FOR WELFARE BENEFITS UNDER THE ABOVE PROGRAMS?

A. Federal SSI rules allow an individual to have:

1. $20/per month income, earned or unearned, from any source;
2. First $65/per month of earned income;
3. Food stamps;
4. Income tax returns;
5. Home energy assistance;
6. Assistance based on need funded by a State or local government;
7. Small amounts of income received irregularly or infrequently;
8. Interest or dividends earned on countable resources or resources excluded under other Federal laws;
9. Grants, scholarships, fellowships or gifts used for tuition and educational expenses;
10. Food or shelter based on need provided by nonprofit agencies;
11. Loans to the individual that must be repaid;
12. Money someone else spends to pay the individual’s expenses for items other than food or shelter;
13. Income set aside under a Plan to Achieve Self-Support (PASS);

14. Earnings up to $7,180 per year (effective January 2016) for a full-time student under the age of 22;

15. Cost of impairment-related work expenses for items or services that a disabled person needs in order to work;

16. Cost of work expenses that a blind person incurs in order to work;

17. Disaster assistance;

18. First $2,000 of compensation received per calendar year for participating in certain clinical trials;

19. Refundable Federal and advanced tax credits received on or after January 1, 2010; and

20. Certain exclusions on Indian trust fund payments paid to American Indians who are members of a federally recognized tribe.

Q. ARE THERE ANY OTHER PROGRAMS AVAILABLE THAT PROVIDE HELP OR SERVICES TO PERSONS WITH DISABILITIES WHO DO NOT QUALIFY FOR LOW-INCOME OR POVERTY PROGRAMS?

A. Yes. There are a number of programs available to help people with developmental disabilities who have limited assets and income, but are not necessarily poor. This third category of benefits is referred to as “sliding scale” benefits. Vocational rehabilitation agencies, mental health agencies, and some United Way funded agencies charge for their services based on the ability of the person with a disability to pay. The amount a person pays for a service is determined by how many persons are in a family, how much money he earns, and how much he owns in assets.

Q. HOW WOULD AN INHERITANCE AFFECT ELIGIBILITY FOR SLIDING SCALE FEE SERVICES?

A. If a person has assets in his name, he may have to pay for the same quality service that he would otherwise receive for free. These services may include case coordination, personal care attendants, vocational training, activities of daily living, residential supervision, money management, etc. If a family member with a disability requires any of these services, a parent should leave the inheritance to the trustee of a special needs trust for the benefit of this individual. That way, the money inherited will go further and will not have to be spent on services and supports that the government or private agencies are able to provide.

Q. HOW DOES A PARENT KNOW IF HIS CHILDREN WILL REQUIRE WELFARE OR SLIDING SCALE FEE SERVICES AFTER THE PARENT OR CAREGIVER DIES?

A. In some cases, it is fairly obvious that the family member with a disability will require all three types of government benefits after the deaths of the parents or caregiver. When a family is not sure if sliding scale fee services or welfare services will be needed, it is recommended that they still plan their estate so that eligibility for welfare or sliding scale fee services will not be jeopardized. They should leave the inheritance meant for the family member with a disability to a special needs trust for the person's benefit. That way, the child will remain eligible for all three types of government benefit programs in the event the child needs these benefits after the parent or caregiver dies.

In addition to writing a properly drafted will and special needs trust, parents need to change the beneficiary on all of their insurance policies, pension plans, IRAs, and other assets that include a named beneficiary. Parents and other family members must remember that naming a person with a disability as the beneficiary of a life insurance policy or other direct beneficiary asset will jeopardize eligibility for government benefits. Rather than name the person with a disability individually, the special needs trust would be named as the beneficiary.

Q. IF A PERSON WITH A DEVELOPMENTAL DISABILITY IS LEFT AN INHERITANCE DIRECTLY, CAN HE GIVE AWAY HIS MONEY IN ORDER TO QUALIFY FOR WELFARE OR SLIDING SCALE SERVICES?

A. If a person has assets greater than the amount allowed by his state of residence, it is generally not possible for him to simply give away money or disclaim an inheritance in order to qualify for government benefits. However, it may be possible to spend down the money on certain goods and services that are considered exempt assets.

Some additional planning options do exist for persons with disabilities whose parents failed to appropriately plan for their future needs. In 1993, the Omnibus Budget Reconciliation Act (OBRA '93) was signed into law. OBRA '93 allows a parent, grandparent, legal guardian, or court to place funds from an unexpected inheritance or lawsuit into a special needs trust for the benefit of the person with a disability. After the funds are transferred to the trust, the person with a disability will be eligible for Medicaid. However, when the person with a disability dies, the state must be reimbursed the amount of Medicaid dollars it has spent on him. While this doesn't preserve the family's assets for any other children who do not have a disability, it will allow a person with a disability to re-qualify for Medicaid benefits and enjoy “supplemental” benefits for life. It is also important to note that OBRA '93 trusts do not preserve eligibility for sliding scale fee services.

CHAPTER 4:

ON THE ROAD TO HOME CONTROL AND OWNERSHIP –

PRESERVING ELIGIBILITY FOR BENEFITS THROUGH ESTATE PLANNING

Estate planning is a particularly complex process for families with a member who has a disability. Virtually everyone finds it difficult to contemplate his own death, but parents of a child with a disability are even more anxious because of concerns about their child's future. It is also not unusual for parents to either feel too young to consider estate planning or to feel that they have so few assets that estate planning is not applicable to them. Regardless of age or size of estate, parents of children with special needs should have a properly written will.

Q. WHY IS WRITING A WILL SO IMPORTANT?

A. Writing a will is important to ensure that a person's assets are allocated to the individual(s) of his choice. A will also allows a parent to name a guardian for a minor child or an adult child with a disability who cannot handle finances or make personal decisions for him or herself.

Q. IF A PARENT DIES WITHOUT A WILL, WON'T THE SURVIVING PARENT SIMPLY RECEIVE ALL OF THE ASSETS?

A. Maybe. If all of the family assets are held in joint tenancy, then the surviving spouse will inherit all of the assets. However, assets not held in joint tenancy will be distributed according to the intestacy rules of the state in which the parent resided at the time of his death.

Q. IF A PARENT DIES WITHOUT A WILL, WILL THE SURVIVING PARENT BE THE GUARDIAN FOR MINOR OR ADULT CHILDREN WITH DISABILITIES?

A. A surviving parent will continue to serve as the legal guardian of the person only of a minor child. This means the surviving parent continues to make daily personal decisions for his minor child, but if the child inherited assets in his or her name the surviving parent must be appointed by the court as the guardian of the child's estate in order to have control over the minor's assets.

Many parents believe that if their adult child has a severe disability, they will continue to have the same power to make personal and financial decisions for their child as they did when they were a minor. This is not the case. When the family member with a disability is an adult, the surviving parent must be appointed by the court to serve as the guardian of the person or of the estate of the adult with a disability. A guardianship of the estate can be a costly and sometimes intrusive means of protecting the assets of a person with a disability. By writing a will that leaves the child's share to a trust, the need for a guardianship of the estate can be avoided.

It is important for parents to understand that by not writing a will, their children will receive a percentage of their assets in the form of an inheritance. If the money is not directed to be paid to a special needs trust, the child with a disability may need a guardian of the estate and may lose eligibility for government benefits.

Q. WHAT HAPPENS IF A PARENT DIES WITHOUT A WILL?

A. Each state has intestacy statutes that determine who will receive an individual's property at death if they dies without a will. Under these laws, which vary from state to state, the property of the deceased person passes on to the surviving spouse and other relatives. In order for property to be passed on to a friend, loved one, charitable organization or trust, a will must have been executed.

The following are <u>general guidelines</u> that most states use to determine the property distribution for an individual who died intestate:

If the person is survived by a spouse and one child, his estate will be divided between them with each getting half of the property. If a spouse and more than one child survive the individual, then the spouse will get only one third of the estate and the other two-thirds will be distributed amongst the children. Please note that a person's spouse is the individual to whom he or she is legally married at the time of death, therefore, domestic partners or former spouses will not inherit property.

If an individual is survived only by children and grandchildren, his estate will be divided equally among his children. If children have predeceased the individual and left grandchildren, then those grandchildren will take the share of the estate that would have been passed to their parent.

If there is no surviving spouse, nor surviving children or grandchildren, an estate will generally pass to an individual's parents, if they are alive. If the parents are not alive, the estate passes to any living siblings. If some or all siblings have predeceased the person, the individual's nephews or nieces will inherit the share of their deceased parent. If the closest surviving relatives are an individual's aunts and uncles, they or their children will get the estate.

If none of the individual's relatives are still living, their property will escheat to the state, meaning that the government will get it all.

Q. IS IT NECESSARY TO WRITE A WILL EVEN IF A PARENT HAS A VERY SMALL ESTATE?

A. Yes. It is best to write a will if:

1) You want your child to receive his share at an age later than 18 years old;

2) You want to be sure your spouse has sufficient income and ownership or benefit of the family home and assets until he or she dies,

3) You want to avoid a guardianship of the estate for your minor or adult children with disabilities;

4) You want to preserve your family member's eligibility for government benefits; and

5) You want to avoid having to obtain a surety bond.

Q. WHEN IS THE BEST TIME TO PREPARE A WILL?

A. Families should not wait until old age to write wills. It is best to prepare a will and estate plan while still in good health and with time to properly plan for the distribution of one's estate at death. Any share of the estate that is for the family member with a disability should be left to a special needs trust so that the family member does not lose eligibility for government benefits. A will should be reviewed every 3-5 years and rewritten to reflect current needs and any change in circumstances. Families typically have three wills during their lifetime: a first will when the children are young, a second when non-disabled children become adults and are frequently named in fiduciary positions such as guardian or executors, and a third in old age when tax planning and final plans are made for the special needs adult child.

Q. WHAT IS A TRUST?

A. A trust is a legal agreement between two or more people where one person, the grantor, places property in the name of another (the “trustee”) or a legal entity such as a bank (the “corporate trustee”) for the benefit of another person (the “beneficiary of the trust”). The trustee owns the property, but has a legal duty to use the property for the benefit of the beneficiary and only according to the terms of the trust document.

Q. WHAT ARE THE ADVANTAGES OF USING A TRUST TO PROVIDE FOR THE BENEFIT OF A FAMILY MEMBER WITH A DISABILITY?

A. An inheritance that is directed to a trust will eliminate the need for a guardianship of the estate in the event the person with a disability is unable to handle the assets. The type of trust recommended for a child who is receiving government benefits or is likely to do so is called a special needs or discretionary trust.

Q. HOW DOES A “SPECIAL NEEDS TRUST” DIFFER FROM A “SUPPORT TRUST”?

A. In a “support trust,” the trustee holds the money for the benefit of the beneficiary, with the duty to pay for the beneficiary's general support. Sometimes a support trust includes “discretionary” language, which says that any distribution of trust assets is at the discretion of the trustee. However, when the beneficiary is receiving government benefits that are either welfare benefits or sliding scale fee benefits, many states have successfully forced the trustee to reimburse the state for the cost of providing state funded services and supports to the beneficiary.

In a “special needs trust” fund, the trust specifically says that the trustee can only distribute assets if such distribution will not jeopardize eligibility for government benefits. All distributions are limited to goods or services that are not provided by the state. In other words, the “special needs trust” fund supplements government benefits rather than supplanting them.

It is important for families and attorneys to keep in mind that the wording of the trust is critical to preserving eligibility for government benefits. A trust which requires distribution of income or principal may disqualify a person from receiving SSI or Medicaid benefits. The quality of the person's life will generally not be enhanced if the income from the trust results in a decrease in government benefits. It is important that parents ask their lawyer if he or she is familiar with “special needs trusts” and the language required to avoid the loss of government benefits. Most general lawyers and even some estate planning lawyers are not familiar with special needs trust funds. You need to be sure your lawyer understands that the trust is to preserve eligibility for government benefits and not just to provide support or avoid the need for a guardian.

Q. IS A WILL THE ONLY WAY TO TRANSFER ASSETS FOR THE BENEFIT OF A FAMILY MEMBER WITH A DISABILITY?

A. No. A parent or other family member can establish a “special needs trust” during their lifetime and make gifts of cash or real estate to the trust. Other family members can also name the trust as the beneficiary in their own will, life insurance policies, pension plans, or Individual Retirement Accounts (IRAs).

Q. HOW DO YOU DECIDE IF IT'S BETTER TO LEAVE A TESTAMENTARY TRUST OR A LIVING TRUST?

A. If the trust is created while the person is still alive, it is called a “living trust.” If the trust is created in a person's (grantor's) will, it is called a “testamentary trust.” Whether you leave an inheritance in the form of a testamentary trust or an inter vivos trust depends upon a number of variables.

A testamentary trust does not go into effect until after the grantor dies. Because it does not exist until the death of the grantor, other relatives who die first cannot make gifts to the trust or name the trust as a beneficiary of their insurance policies or wills.

A living trust is established while the grantor is still alive. The parent can choose to leave the trust largely unfunded until he diesw, at which point the trust will be more fully funded. The parent also has the option of transferring some but not all of his or her assets to the trust while still alive. Another advantage of a living trust is that other persons can make gifts to the trust or designate an inheritance for the person with a disability in their own wills by naming the trust as beneficiary.

In summary, the big difference between a living and a testamentary trust is that the living trust can accept gifts as soon as it is created. The testamentary trust does not come into existence until the person who has provided for it in his will dies.

There are a few other probate and tax laws which may affect the choice between a living and a testamentary trust. For example, if the parent wants to name a successor trustee who lives out of state, the parent may need to preserve that option by creating a living trust. For a full explanation of the advantages and disadvantages of a living trust versus a testamentary trust, parents should consult an attorney who is skilled in the area of trust and tax laws.

Q. HOW DOES A PARENT CHOOSE A TRUSTEE?

A. A critical issue in leaving money in any trust, and certainly a special needs trust, is the selection of the trustee. The person chosen needs to be responsible, trustworthy, and competent to invest and distribute the funds appropriately. The choice of a trustee depends on a number of variables, including the following:

- Size of the trust estate;
- Availability of family members as successor trustees;
- Appropriateness of corporate trustee;
- Funding of the trust during parent's lifetime;
- Estate Tax planning;
- Relationship between trustee and beneficiary.

While a trustee remains legally responsible for investment and distribution decisions as well as filing appropriate tax forms, he does not necessarily have to do all of this work alone. The trustee is encouraged to hire or consult with a financial planner, accountant, attorney or other professional for assistance managing the money held in trust.

Q. WHAT HAPPENS IF THE PERSON NAMED TO SERVE AS TRUSTEE DIES BEFORE THE BENEFICIARY?

A. In almost all cases, a successor trustee is named in the trust. If the trust document does not provide for a successor trustee, the court will name one. The court will usually name a bank to serve as successor trustee. If the parent prefers that a family member serve, this should be indicated in the trust document. It is recommended, whenever possible, to name at least two or three successor trustees in the trust. A parent can also give the last named trustee who serves the power to name an additional trustee to succeed them. This is especially wise when a parent is considering grandchildren as successor trustees.

Q. HOW DO FAMILIES DETERMINE IF THEIR LAWYER IS COMPETENT TO DRAFT A SPECIAL NEEDS TRUST FOR THE BENEFIT OF A FAMILY MEMBER WITH A DISABILITY?

A. Families with special estate planning needs have to be particularly careful when interviewing lawyers to draft their estate plan. They cannot assume that every attorney is knowledgeable about special needs trusts. This topic is rarely, if ever, covered in law schools, and most lawyers are not aware of the special estate planning issues concerning the preservation of government benefits.

Even though a family attorney may be knowledgeable about wills and trusts, he or she may not be able to write a supplemental needs trust that will preserve the family member's eligibility for needs-based benefits. Drafting a special needs trust requires knowledge of a highly specialized area of law.

The following additional recommendations may assist the attorney who is inexperienced in drafting special needs trusts:

1. In order to educate themselves about special needs trusts, attorneys should review the legal literature on this topic. Several excellent articles have been written on this subject and are included in Appendix D.

2. The trust language should direct the trustee to purchase goods and services on behalf of the beneficiary and to not give the beneficiary money directly. It is important to remember that distributions of cash are considered unearned income and any distribution over $20 per month may jeopardize eligibility or result in a decrease in benefits.

3. The beneficiary must not have the power to demand disbursements from the trust. All disbursements from the trust must be in the sole discretion of the trustee, reflecting the stated intent of the settlor not to jeopardize benefits.

4. Mandatory support language which refers to trust assets being used "for the general care, comfort and welfare" of the beneficiary should be avoided.

5. The trust should include traditional "spendthrift" language to protect the trust assets from private creditors.

6. Care must be taken to assure that any "boilerplate" language be appropriately modified before being included in a special needs trust. For example, many trusts give the trustee the authority to disburse smaller trusts to the income beneficiary which is clearly inappropriate for a special needs trust.

7. It is recommended that the trust contain "self-destruct" language directing distribution of the trust assets to a secondary beneficiary in the event the trust ever becomes subject to reimbursement to the state. It is highly unlikely that this will happen, but the mere presence of a "self-destruct" clause may act as a disincentive to a state challenge of the trust.

Q. ***IF A FAMILY HAS ALREADY PREPARED A TRUST, HOW DO THEY KNOW IF IT IS A SPECIAL NEEDS TRUST?***

A. The major difference between a special needs trust and a support trust lies in the language used in the introductory portion, where the intent of the trust is stated. If the trust says "the primary purpose of this trust is for the care, support and maintenance of my son or daughter..." the trust is a support trust. It may have discretionary language, but its primary purpose is support, the language may jeopardize the beneficiary's eligibility for government benefits.

A special needs trust will have language similar to the following:

> "All funds allocated to this trust are to be administered by the trustee solely for the benefit of the beneficiary. The beneficiary is disabled and the express purpose of this trust is to provide for the beneficiary's extra and supplemental needs, over and above the benefits she otherwise receives as a result of her handicapping condition from any local, state or federal governmental source or from private agencies any of which provide services or benefits to persons who are disabled. By way of illustration, the trustee may purchase those goods or services which shall enhance the beneficiary's development and happiness, including but not limited to: entertainment items, evaluations, training and educational programs, transportation to visit relatives and friends (or for relatives or friends to visit the beneficiary), and the like all of the above to the extent not otherwise provided by federal, state or local governmental agencies and departments. Anything to the contrary herein notwithstanding, no trust income or principal shall be paid to or for the benefit of a governmental agency or department or used as reimbursement or otherwise to supplant or replace benefits received by the beneficiary for her care, comfort and welfare from federal, state and local governmental agencies and departments. The trustee shall first look to such governmental funds before making any payments from the trust estate and shall use trust assets only to supplement and never to substitute for such funds. In no event may trust income or principal be paid to or for the benefit of a governmental agency or department and the trust estate shall at all times be free of the claims of such governmental bodies."

Q. ***HOW CAN A TRUST INCREASE THE ABILITY OF A PERSON WITH A DISABILITY TO OWN HIS HOME?***

A. A properly worded trust can provide the funds for the supports and services which the government does not provide but which are needed by a person with a disability in order to live in his own home. The money held in trust can be used to buy household furnishings, adaptive equipment, electronic security devices, housekeeping services, a companion or an advocate. When these services are combined with assistance from Medicaid, community and home support services, an agency that provides services to persons with developmental disabilities, and assistance available from subsidized housing programs, many persons with developmental disabilities are able to live in their own homes or apartments.

Q. ***WHY CAN'T PARENTS JUST LEAVE THE FAMILY HOME TO THE FAMILY MEMBER WITH A DISABILITY?***

A. While a home is an exempt asset, it is not recommended that a person who requires government assistance be left a home outright. The home is an exempt asset only as long as the person with a disability lives in the home. If the person with a disability requires prolonged nursing home care or when he dies, the home loses its exempt status. Often, a home is a family's greatest asset. If there are other children who receive a smaller inheritance because the child with a disability was left the family home, there may be hard feelings.

Leaving the home outright to the family member with a disability is like making a future gift to the State. If the family member is not able to live in the home, the State will force a sale of the home and require the person to pay privately for his care until the proceeds from the sale of the home are spent down to the poverty level. Also, upon the individual's death, the State will place a lien on the property and reimburse itself for the cost of services provided to the individual during his lifetime.

Leaving the home to a person with special needs may trigger the need for a guardianship of the estate. If the person incurs debts, creditors may be able to force a sale of the home. Leaving the home to a trust reduces the risk of this outcome. Home ownership is a complicated area of law that should be discussed with a specialist in this field.

Q. ***SHOULD PARENTS CONSIDER LEAVING THE HOME TO A SPECIAL NEEDS TRUST FOR THE BENEFIT OF THE FAMILY MEMBER WITH A DISABILITY?***

A. In some cases, leaving a home may be appropriate. However, parents must also be sure that the trust is funded with adequate cash assets to be able to pay for necessary home maintenance, repairs, insurance and taxes. It is also important for the trustee to be familiar with how distributions from the trust can affect the person's continued eligibility for government benefits.

For example, the trustee has to be aware of how providing income directly to the person who is receiving government benefits may affect their benefits. The receipt of unearned income will result in a reduction of SSI income to pay other necessary expenses. The amount of money a beneficiary receives from SSI will also be jeopardized if the trustee pays for food, or shelter, or provides more than $20 per month in spending money.

A trustee is able to make payments from the trust for telephone service, residential assessment fees, yard work, housekeeping, laundry service, etc. without reducing the amount of the beneficiary's SSI check. If a trustee is unfamiliar with how distributions can or cannot be made, the trustee should hire an attorney or advocate who is knowledgeable in this area prior to making distributions from the trust.

Q. SHOULD A TRUSTEE GIVE THE BENEFICIARY OF A SPECIAL NEEDS TRUST FUND SPENDING MONEY?

A. No. If the beneficiary is receiving needs based benefits such as SSI, Medicaid, Section 8, etc., a trustee can jeopardize eligibility for SSI and/or Medicaid by distributing spending money directly to the beneficiary. The trustee needs to know that money received as gifts is counted as "unearned income." If a person receives more than $20.00 in spending money each month, the SSI check will be reduced by the same amount. If the trustee gives an SSI recipient $100 per month spending money, his check will be reduced by $80. The recipient can keep the first $20 without it being counting against him, but the additional $80 in spending money will result in a direct reduction in his SSI check.

Q. HOW CAN A TRUSTEE AVOID THE LOSS OF SSI WHILE STILL PROVIDING THE BENEFICIARY WITH EXTRAS HE CANNOT AFFORD?

A. A trustee can pay for a number of expenses that will subsidize the cost of owning a home and enhance the quality of the beneficiary's life without jeopardizing eligibility for SSI. For example, the trustee can pay for residential maintenance or assessment fees, telephone service, repair, lawn care, housekeeping and laundry services, household furnishings, security devices, non-food grocery items such as paper goods and personal hygiene products, transportation, companion and advocacy services. The trustee can also pay for services and products such as haircuts, manicures, pedicures, and entertainment expenses.

The important thing for the trustee to remember is that the trustee cannot pay for food, and shelter without jeopardizing the loss of one third of a beneficiary's SSI check. The trustee should also remember that payment for the allowable examples listed above must go directly to the provider. The trustee cannot give the beneficiary the cash to purchase the above goods or services. All payments from the trust must go directly to the provider or vendor selling the service.

CHAPTER 5:

DEVELOPING A PUBLIC/PRIVATE PARTNERSHIP – INCREASING HOUSING OPTIONS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

By using both public and private funds, a person with a disability is often able to enjoy a more independent lifestyle than he would otherwise. Many families are simply not in a financial position to leave sufficient assets in trust to enable the trustee to purchase a home outright, maintain the home for the beneficiary's lifetime, and pay for all the support services necessary for independent living. However, by combining the assets of a trust with federal housing programs and support services, home ownership can become a reality for many persons with a developmental disability. On January 16, 2014, the Centers for Medicare and Medicaid Services published the Home and Community Based Services final rule setting forth new requirements for Medicaid waivers. The intent of this rule is to maximize opportunities for people with disabilities to have access to the benefits of community living, including receiving services in the most integrated setting. The rule emphasizes personal autonomy, community integration, and choices for people who chose home based or community services.

Q. HOW CAN FEDERAL HOUSING PROGRAMS HELP A PERSON WITH A DISABILITY TO PURCHASE A HOME?

A. There are a number of financing programs available to persons who have a disability and/or are low-income. These programs reduce the cost of housing in the following three ways:

- Reducing the cost of the property;
- Reduce the cost of financing the property; or,
- Subsidize the availability of cash to make the purchase affordable.

Q. WHAT CAN FAMILIES DO TO ENSURE THAT THEIR FAMILY MEMBER IS ELIGIBLE FOR FEDERAL HOUSING PROGRAMS?

A. Families need to become familiar with the types of housing that are available for persons who want to live independently, but have limited resources. Many people who are poor and do not have enough money to live alone do so with the help of welfare benefits and housing subsidies. There are various kinds of welfare programs and housing subsidies at the federal, state, and community level. Families must identify the particular standards and regulations of each program and then write a will and/or special needs trust which will not disqualify their family member from being eligible for these programs.

Q. WHAT IF THE FAMILY IS OPPOSED TO THE USE OF THE WELFARE SYSTEM AND DOES NOT WANT THE MEMBER OF THE FAMILY WITH A DISABILITY TO BE "ON WELFARE?"

A. Some families, for personal reasons, are opposed to welfare programs. In such cases, the family should meet with a financial planner to maximize the family resources available to subsidize the housing and support costs for the member with a disability. The family may also want to ask their church community, friends, and extended family members to provide the supplemental support that their child may need to live independently. Generally, developing a private network of support that lasts the lifetime of the member with a disability is difficult unless a family has sufficient resources or a large network of church, friends, and family support.

By planning to preserve eligibility for welfare type benefits, the family provides a back-up support system in the event private supports prove to be inadequate. If the individual's natural support network is unable to meet his needs, the family can then turn to the government for assistance. Preserving eligibility for government benefits thus increases the number of housing options available.

Q. WHAT FEDERAL HOUSING PROGRAMS ARE AVAILABLE TO ASSIST A PERSON WITH A DISABILITY TO PURCHASE A HOME?

A. One way to reduce the cost of independent living is through the purchase of a home with reduced financing costs. Families and individuals can get very affordable deals on homes which have been repossessed. When a person fails to pay his mortgage payments, the bank is allowed to foreclose on these loans and claim ownership of the property. Because banks are often anxious to sell these homes quickly in order to minimize their loss on the unpaid mortgage, foreclosed properties often sell for below market value. Information regarding foreclosed properties can be obtained from the following sources:

1) **The Federal Deposit Insurance Corporation (FDIC)** - The FDIC will provide a list of foreclosed properties that are for sale. This list contains the name, address, description and price of the properties, as well as contact persons and phone numbers.

2) **Home Mortgage Fund Providers** - The Fannie Mae and Freddie Mac corporations purchase home mortgages and work with lenders to provide mortgage loans to individuals and families with limited incomes. Online databases often list Fannie Mae and Freddie Mac properties for sale alongside those offered by the FDIC.

3) **Housing and Urban Development (HUD)** - HUD takes over properties insured through the Federal Housing Administration (FHA). Because HUD tries to dispose of these properties quickly, one can often purchase homes for below-market price.

I. Reducing the down payment or financing costs of a home can also increase its affordability for first time and low-income buyers. The following programs provide this type of assistance:

A) **The Section 502 and Section 515 Programs** - The U.S. Department of Agriculture administers several housing assistance programs, known collectively as the Rural Housing Programs. The Section 502 Program finances the purchase, construction, or repair of single-family homes for individuals who are low or very low-income. The Section 515 Program offers very low to moderate income families low interest loans to finance multifamily or congregate housing.

B) **Shelter Plus Care** - This program offers rental assistance to homeless persons with disabilities in conjunction with outside-funded supportive sources. The funds are available for any of four assistance types, the most appropriate for individuals with disabilities being tenant-based rental assistance (TRA). TRA participants reside in housing of their choice (barring any requirements based on supportive service availability), which is funded for a contract term of five years. Arguably, all persons with a disability may be considered at risk for homelessness, as their parents are not required to supplement their support as adults. Those individuals whose families are no longer able to support them are thus eligible for this program.

C) **The Community Reinvestment Act (CRA)** - The CRA requires banks to invest in the community they serve. Honest assessment of the financing needs of the community, especially its low and moderate income neighborhoods, leads many banks to earmark large sums of mortgage money for community investment. Under this Act, a bank may allow an individual to take over a mortgage on a foreclosed property. By taking over an existing mortgage through the CRA, a low or moderate income person must only repay the amount outstanding on the mortgage, and thus may take advantage of below-market rates and/or no down payment. As a result of changes to the Act made in 1989, banks are now required to make public disclosure of its CRA rating. While the Act does not demand that banks give more favorable terms, many do, as they will not meet community investment standards unless enough individuals and families can qualify for home purchases. Lenders will seldom inform the buyer of these terms, so buyers need to be aggressive in pursuing a mortgage through the CRA with the best possible terms.

II. There are several housing assistance programs that allow funds to be used in many different capacities, often allowing local or state offices and/or governments to dictate how the funds will be distributed or used in a specific community. Two such programs are:

A) **Community Development Block Grants** - Funded by HUD, these grants are administered through local community development offices. The funds may be used to purchase or to rehabilitate residential properties and are available only to low and moderate income individuals or families. States have a great deal of flexibility as to how these funds are used. Strong advocacy on the part of agencies and consumers can greatly impact the availability of these funds to persons who are disabled.

B) **The HOME Program** - The HOME Program is the largest Federal block grant to state and local governments. The program is extremely flexible, allowing each government to design its own housing strategies to meet local needs. Every five years a Comprehensive Housing Affordability Strategy (CHAS) determines how the HOME funds are to be utilized to best aid low-income persons in the acquisition of affordable housing. The five year plan is updated every year so that it reflects the changing needs of each individual community. Because this blueprint is developed on a local level, advocates can aid in the development of the plan to ensure that the program is specifically responsive to the needs of persons with disabilities. HOME funds can be provided to persons on waiting lists for the Section 8 program, be used to rehabilitate rental or homeowner properties, and may even be used to construct new property. The HOME program bridges the gap between the financial means of potential homeowners and the market cost of housing in their community.

C) **Housing Choice Voucher Program (HCVP)** – HCVP is the most commonly used form of housing assistance for low-income. Originally created in 1975, the HCVP is an attempt to increase the housing options of low-income individuals and reduce the concentration of low-income households in particular neighborhoods. The HCVP tenant-based assistance allows individuals and families to select private rental housing from a list of approved properties in their community. Tenants generally pay between 30% and 40% of their income in rent and the remaining rent is covered by a voucher paid directly to the landlord by a local Public Housing Authority (PHA). One of the major drawbacks of this program is that it can be difficult to find landlords who are willing to participate, as they must agree to accept the "fair market rate" determined by HUD. This so called "fair market rate" is often below the real market rate, thus forcing landlords to accept a lower rent than they might otherwise receive. Despite this obstacle, the HCVP tenant-based assistance has proven extremely successful and quite popular. The other, less commonly used types of housing assistance provided by the HCVP are in the form of project-based rental assistance, homeownership assistance, and down payment assistance.

Q. IF THE FEDERAL GOVERNMENT PROVIDES ASSISTANCE IN FINDING AFFORDABLE HOUSING AND THE STATE PROVIDES SUPPORT SERVICES, ARE PRIVATE FUNDS STILL NEEDED?

A. Yes. A properly drafted trust fund can mean the difference between a person with a disability succeeding in his own home or not. One of the first things a family needs to address is how much money and how many support services the person with a disability will need to live independently. It is important to understand that, because of its limited resources, the state provides only the minimum amount of services needed by a person. Without additional supports, the family member may not be able to remain in his or her own home and may have to move to a more sheltered, segregated living arrangement.

Q. HOW DOES A FAMILY DETERMINE HOW MUCH MONEY IS NEEDED TO SUPPLEMENT THE COST OF HOUSING AND SUPPORT SERVICES PROVIDED BY THE GOVERNMENT?

A. It is recommended that families sit down with a financial planner who is knowledgeable about future goals for lifetime care of a person with a disability. The family should develop a list of all expected expenses associated with living independently and compare this list of expenses with the amount of anticipated income that the individual with a disability will receive on a monthly basis. In short, they should develop a budget which will provide for all of the supports and services needed by the family member to live in a home of his own.

Q. WHAT KIND OF EXPENSES SHOULD BE INCLUDED IN THIS BUDGET?

A. Developing a housing budget for a person with a disability is not very different from developing a budget for a person without a disability. At a minimum, the budget should include: rent or mortgage payments, heat, electricity, water and sewer, phone, maintenance, taxes, insurance, garbage pickup, food, clothing, transportation, personal hygiene needs, recreation and leisure time expenses. The family will also have to include the cost of adequate support services, including the cost of benefits such as workmen's compensation and the payment of Social Security taxes. A sample budget is included in Appendix F. By combining the assets of a trust with federal and state housing and community support money, home ownership can become a reality for many persons with a developmental disability. The trust can also pay for household furnishings, electronic security devices, housekeeping and grounds keeping services, a companion or an advocate. While these services are seldom funded by the government, they are often needed by a person with a disability in order to live independently.

Q. WHAT STRATEGIES ARE RECOMMENDED BY FINANCIAL PLANNERS TO MAXIMIZE THE FAMILY'S RESOURCES?

A. There are several investment strategies available to maximize the estate parents have to leave their children. Parents may want to consider purchasing a “second to die” life insurance policy which provides a larger payment to the child's trust when the second parent dies. A “second to die policy” is a single life insurance policy that acts on the lives of two people where the insurance company pays a death benefit only when the second person dies. The rates for this type of policy are generally substantially lower than the rates on individual policies. A financial planner may also recommend purchase of a tax sheltered annuity as a means of funding a special needs trust at a higher level than the parents' immediate resources are able to fund. There is no one answer as to how much money to leave to a special needs trust fund. Parents must take the time to develop a budget to determine how much money they believe is needed to supplement the cost of lifetime care. The goal is, clearly, to fund the trust with sufficient assets so that the income from the trust will be sufficient to provide the supplemental services needed by the family member. If a trustee must routinely dip into the principal of the trust to pay for needed expenses, the trust is less likely to last the beneficiary's lifetime.

Q. ARE THERE SPECIAL RULES THAT APPLY TO HOW THE TRUST FUNDS CAN BE USED?

A. A properly worded special needs trust will allow the trustee to spend assets for the sole benefit of the beneficiary, but only in a manner which will not jeopardize the beneficiary's eligibility for government benefits. At no time can the trustee distribute cash directly to the beneficiary. All distributions from the trust must be made directly to the vendor. In addition, any distributions from the trust for food, and shelter will result in a one third reduction in SSI benefits.

Q. ARE THERE SPECIAL RULES THAT APPLY TO HOW THE TRUST FUNDS CAN BE INVESTED?

A. A trustee can invest the trust estate in any reasonably prudent manner. Unless so authorized, the trustee cannot make risky investments that could result in the loss of the trust assets. Obviously, the goal should be to maximize the amount of income earned while providing sufficient funds to draw on during the year. It is often important that the trustee receive advice from a professional in regard to investments and certainly in regard to distributions from the trust.

Q. WHO PAYS THE TAXES ON THE MONEY EARNED BY THE TRUST?

A. Each year the trustee will file a trust tax return with the IRS. The amount of taxes due will depend on a number of variables, such as: how the funds are invested and how the funds are distributed during the year. The trustee must account for all income earned and all distributions from the trust. If the trustee is not familiar with how to file a trust income tax return, he should hire an accountant or tax attorney to file the annual income tax return and to advise him on tax matters relating to the trust investments.

Q. WHAT HAPPENS TO THE MONEY LEFT IN THE TRUST AFTER THE FAMILY MEMBER WITH A DISABILITY DIES?

A. Generally, the grantor specifies where the money will go when the family member with a disability dies. Often the funds are distributed to the beneficiary's brothers and sisters or given to a favorite charity. Where the money goes is completely up to the grantor to decide and should be incorporated into the trust document before the trust is signed. When the beneficiary is capable of designating remaindermen, the grantor can allow them to do so by giving the beneficiary a limited power of appointment. It is critical that the beneficiary not be given a general power of appointment. A general power of appointment enables the state to demand all the funds remaining in the trust be left to the state.

CHAPTER 6:

VARIOUS WAYS OF HOLDING PROPERTY

In order to better understand housing options, it is helpful to understand the various ways that property can be held. The following are explanations of the advantages and disadvantages of owning property as an individual or jointly:

1. PROPERTY OWNED IN ONE'S NAME ALONE

A person can hold title to property in his name alone. One of the advantages of sole ownership is that the owner can do as he pleases with the property. However, as a sole owner, an individual is totally responsible for paying all of the costs associated with maintaining the home. It is important to note that home ownership does not exclude an individual from being eligible for most government benefits, including Medicaid and SSI. A home is an exempt asset as long as the individual or that individual's spouse or dependent child lives in the home as his principal place of residence. A problem will arise, however, if the individual leaves the home for six months, as the state may then force a sale of the home and file a claim for reimbursement for all Medicaid benefits paid during any period of ineligibility. In these cases, the home will also become part of the individual's estate when he or she dies. Changes in Medicaid regulations resulting from OBRA ’93 allow the state to seek reimbursement against an individual’s estate for any Medicaid payments made on his behalf during his lifetime. Therefore, it may not be advisable for a person with a disability to own a home in his own name if he is a recipient of needs-based government benefits.

2. PROPERTY OWNED IN JOINT TENANCY

Assets such as bank accounts, real estate and an automobile may be owned in joint tenancy. Joint-tenancy with rights of survivorship means that all of the owners have the right to use the property, regardless of who originally purchased or owned the property. A tenant’s interest in the property ends at his death and the surviving joint tenants get the deceased tenant's share of the property. One of the advantages of joint tenancy is that property held in joint tenancy does not go through probate at the time of the first joint tenant's death. Joint tenancy may be a good estate planning tool to provide for the disposition of property to another individual, as the survivor will get the property instantly, free of probate costs. Joint tenancy is most commonly used among married couples. It is seldom used when two or more unrelated persons are simply sharing ownership of the home. Usually a person will want to preserve the value of his share of the property and pass it on to this heirs.

3. PROPERTY OWNED AS TENANTS BY THE ENTIRETY

Ownership as tenants by the entirety is a form of real property ownership available only to married couples for their primary residence. Like joint tenancy, the real property passes automatically to the survivor by operation of law upon the death of one owner. It also offers the additional feature that a creditor cannot reach the property unless it is for an obligation owed by both. That is, if the husband owes a debt for which the wife is not also responsible, the property cannot be reached to satisfy the debt.

4. PROPERTY OWNED AS TENANTS IN COMMON

Tenants in common have the right to use and share the same property. Each tenant in common owns a share of the legal title to the property in his name alone, and may transfer ownership of his share to a third party. When he dies, his interest in the property does not pass automatically to the surviving co-tenants as it does in joint tenancy. Instead, it is distributed as part of the deceased tenant's estate to his heirs according to state law or to the beneficiaries mentioned in his will, if a will has been written. As with sole ownership, the state may place a lien on the estate of an individual who has received Medicaid benefits during his lifetime. One of the advantages of owning property as tenants in common is that each tenant shares the expenses and responsibility of maintenance with others. However, if a co-tenant receives government benefits, the state might make a claim against his share if he moves out of the home. This is possible because the state can separate his share from that of the others.

5. PROPERTY OWNED IN A LAND OR REALTY TRUST

With a land trust, the trustee, typically a bank, holds legal title (ownership) to the real estate. The beneficiary or beneficiaries of the land trust are designated by the trust document. In addition, the trust document grants a person or persons the power of direction to direct the land trustee to act with respect to the real estate (i.e. to sell, lease, or mortgage the real estate). The land trust agreement can also spell out who is to get the land upon the death of the beneficiary. The state's ability to place a lien on the property depends on who has placed the property into the land trust and who has authority to sell, lease, or control the property. A land trust offers greater privacy with regard to the ownership of the property and may be appropriate when a parent or individual wants to leave a life estate (i.e. the right to live in the house for one's lifetime) to one person, but future ownership of the property to another.

6. PROPERTY OWNED IN A TRUST

Property that is held in a trust is owned by the trustee for the benefit of another. While it is possible to be both the trustee and beneficiary of a living trust, such an arrangement is not recommended if the beneficiary is receiving government benefits. The state will perceive the ownership to be the same as sole ownership and will place a lien on the property for payment of past services upon the death of the beneficiary or in the event the beneficiary is no longer able to reside in the home. Ownership and control of property by trusts is discussed more fully above.

7. PROPERTY HELD BY SEVERAL OWNERS

The two most common forms of shared ownership are condominiums and cooperatives.

Condominiums are living facilities in which an individual has both individual ownership of their own unit as well as shared ownership of the common areas of the home/building. While most people tend to think of condos as individual apartments within one large building, a condo could be individual ownership of one's bedroom in an individual home with shared ownership in the common areas such as the hallway, bath, kitchen, living and dining rooms. Such an arrangement can be very practical if a person with a disability wishes to share his home with roommates.

Because the building may no longer be considered a “single family” residence, it may require the approval of government agencies to meet zoning requirements for multiple residents. Resale and financing may also prove problematic, and zoning charges, legal fees, and surveying costs could be very high.

Cooperative Housing is another shared arrangement which carries a few more risks than condominiums. Cooperative housing units can include interest in townhouses, individual apartments within a large apartment building or individual bedrooms in a single family home. Each of the co-op members owns stock in the cooperative and has the right to live in a single unit. Each co-op member pays a proportional share of the maintenance, taxes, mortgage payments, etc. and agreement must be reached among all members as to what repairs are to be made. Members also have approval rights of all new co-op members, a provision that can be a negative, as the individual co-op member who wishes to sell can only sell his share to an approved new co-op owner. Another drawback is that if one co-op member does not pay his share of the mortgage, taxes or maintenance, the other members will be responsible for the delinquent owner's share. This is a major distinction between co-operative housing and condominiums. In a condo, if an owner doesn't pay his mortgage, the bank can only foreclose on the delinquent owner's unit, and not the entire building. Despite the risks, however, living in cooperative housing is a viable and somewhat popular option for persons with disabilities.

APPENDIX A:

FEDERAL LAWS AND COURT DECISIONS AFFECTING HOME OWNERSHIP AND CONTROL

On the Federal level, the three major laws that have prohibited discrimination against persons with disabilities are the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, and the Fair Housing Amendments Act of 1988. The first part below is about Section 504, which concerns itself with the right of all persons with disabilities to participate fully in community life. The statute prohibits discrimination against persons by any agency, organization or program receiving federal financial assistance, including all federal housing programs that are designed to help persons who are low-income rent or purchase a home of their own. The HUD regulations were written to comply with Section 504 and require that persons who are disabled are not discriminated against in obtaining access to low cost housing. The second section is about FHAA and the final section gives some updates on recent case law.

SECTION 504 CASE LAW

There have been a number of legal challenges to specific housing authority procedures and regulations based upon the protection and rights as defined in Section 504 and the Fair Housing Amendments Act. The following cases successfully resolved issues concerning tenant disputes and challenged restrictive zoning, health, and safety rules.

In *Cason v. Rochester Housing Authority,* 748 F. Supp. 1002 (W.D.N.Y. 1990), the court held that use of the "independent living" standard violated both the Federal Housing Amendments Act and Section 504. The Public Housing Authority in Rochester, New York was found to violate Section 504 when it rejected three applicants with disabilities because they determined that the applicants were incapable of living independently. The applicants, who were physically disabled, required the assistance of personal care attendants. The court found that the use of the "independent living" eligibility criteria for public housing tended to discriminate against those with handicaps, causing the individuals with disabilities to be considered by a different standard than able-bodied applicants. Therefore, the Court found the "independent living" standard to be a clear violation of federal law and struck it down. This case stands for the proposition that criteria was judging housing applicants must be the same for able-bodied individuals and individuals with a disability. Recent cases have maintained the *Carson* holding regarding the "independent living" standard. See: *Jaininey v. Maximum Independent Living,* No 00-879, slip op. (N.D. Ohio Feb. 1, 2001); *LaFlamme v. New Horizons, Inc.*, F.Supp.2d 378 (D.Conn. 2009) (discussed below).

In *Citywide Associates v. Penfield,* 409 Mass. 140, (1991), a landlord attempted to evict a tenant with a history of mental illness. The tenant's rent was subsidized through a Section 8 voucher. The tenant heard voices and, in order to quiet the noises, threw water and banged on the walls with a broomstick, causing property damage. The landlord refused to allow the tenant to stay even though she agreed to enter an outpatient treatment program. The court held that the tenant was protected by Section 504 and that the proposed accommodation of counseling was reasonable. The court looked at the greater harm that would come to the tenant if she were evicted and became homeless. The court ordered the landlord to allow her to stay in the apartment while receiving counseling. From this case, we learn that courts will examine the totality of harm weighed against a reasonable accommodation when making a determination regarding an eviction.

In *Worcester Housing Authority v. Santis*, No. 89-SP-0471(Mass. Trial Ct, Housing Ct., Worcester County, 1989), the tenant had physical disabilities and was often unable to admit support service providers to her apartment. The housing authority argued that it did not have sufficient staff available to admit the service providers when the tenant could not. The court ruled that the housing authority had failed to reasonably accommodate the tenant's handicapping condition and, therefore, refused to order the eviction. The lesson of this case is that a housing authority is required by law to provide reasonable accommodation to persons with disabilities and that an excuse of insufficient staff will not be upheld by a court.

FAIR HOUSING AMENDMENTS ACT OF 1988 CASE LAW

While Section 504 has been used to protect the rights of persons receiving HUD assistance, historically, there was little that could be done to protect persons with disabilities from the prejudice of hostile neighbors, fearful landlords, or paternalistic legislators, who sought to “protect” persons with disabilities by controlling their housing options for them. Not only were there the usual problems of availability of support services and affordable housing to deal with, but also the unfounded fears and prejudices of the community as a whole.

The Fair Housing Amendments Act (FHAA) of 1988 strengthened the rights of persons with disabilities and helped combat community prejudice. The strength of the FHAA increased with the passage of the Americans with Disabilities Act (ADA) in 1990, the language of which has been used by the courts to interpret ambiguous language in the FHAA, thereby increasing the number of victories for persons with disabilities. The FHAA is effective as a shield against prejudice because it applies to all landlords, lending institutions, and persons in the community, not just parties, receiving federal funds.

The purpose of the FHAA is threefold: 1) to end segregation of the housing available to persons with disabilities; 2) to give persons with disabilities the right to choose where they want to live; and 3) to require reasonable accommodation to their handicapping condition in obtaining housing. One of the strengths of the FHAA is the fact that an individual does not have to prove that a landlord or regulation intends to discriminate, he needs only prove that the challenged housing practice has a discriminatory effect on him as a person with a disability. The law is extremely broad and even protects persons with disabilities from private actions on the part of their neighbors, which interfere with their enjoyment of their home. The FHAA requires accommodations for a disability “if it is reasonable and necessary to afford a handicapped person the equal opportunity to use and enjoy a dwelling.” *Essling’s Homes Plus, Inc. v. City of St. Paul*, 356 F.Supp.2d 971 (D.Minn. 2004). An accommodation is determined to be reasonable if it is both “efficacious and proportional” to the costs to implement it. An accommodation is necessary if it will "affirmatively enhance a disabled plaintiff's quality of life by ameliorating the effects of the disability." *Developmental Service of Nebraska v. City of Lincoln*, 504 F.Supp.2d 714 (D. Neb. 2007).

The following cases were decided based on the FHAA:

In *U. S. v. Scott*, 788 F.Supp. 1555 (D.Kan. 1992), the district court found that a couple's threats to sue their neighbor if he sold his home to an organization that wanted to open a group home violated the FHAA "interference" prohibition. In Virginia, the court held, in *People Helpers Foundation, Inc. v. City of Richmond*, 781 F.Supp. 1132 (E.D.Va. 1992), that neighbors who made derogatory comments to and frequent filed unfounded complaints about tenants with disabilities to the police department violated the civil rights of the tenants. The issue was whether or not the actions of the neighbors amounted to coercion, intimidation, threats, or interference as protected by Section 3617 of the FHAA. The court held that a threat need not involve violence to be actionable under the FHAA. As a result of both *Scott* and *People Helpers*, it becomes clear that private citizens who improperly use the courts or the police to harass persons with disabilities can be sued for their actions. As a result of the FHAA, individuals and service providers have been successful in challenging zoning laws and health and safety restrictions that have the effect of limiting a person's living choices. With regards to unlawful interference under the FHAA, the court, in *West v. D.J. Mortgage, L.L.C.*, 2016 WL 827248 (N.D. Ga. 2016), determined that a plaintiff asserting an interference claim under the FHAA must allege that: 1) the plaintiff is a member of a protected class under the FHA; 2) who was engaged in the exercise or enjoyment of a right protected by the FHA; 3) the defendant coerced, threatened, intimidated, or interfered with the plaintiff's exercise of those FHA rights; and 4) defendant was motivated, at least in part, by an intent to discriminate.

One way that organizations have blocked the development of community residences has been to require a space requirement in their zoning laws. A zoning law may require, for example, that group homes for persons with disabilities be at least one mile apart from each other. These spacing rules were found to be invalid by the court in *Horizon House Developmental Services, Inc. v. Township of Upper Southampton*, 804 F.Supp. 683 (E.D.Pa. 1992). The court held that in imposing the spacing requirement against Horizon House, the city violated the reasonable accommodation provision of the FHAA. The court stated that such a spacing restriction was invalid because it imposed a quota on the number of people with disabilities who could live in a community rather than allowing them to live wherever they liked. A similar zoning restriction requiring notification to residents whose property was within a 1,500 foot radius of the proposed group home location was held facially discriminatory and was not warranted by unique and special needs of the municipality. *Larkin v. State of Michigan Department of Social Services*, 89 F.3d 285 (6th Cir. 1996).

In 2013, the U.S. District Court for the Middle District of Louisiana expanded on the holding in *Horizon House*. Using the approach of an earlier case, *Schwarz v. City of Treasure Island*, 544 F.3d 1201 (11th Cir. 2008), the court considered the discrimination claim of a group home for recovering alcoholics and drug addicts under the FHAA, using the three elements of a reasonable accommodation analysis: 1) refusal, 2) reasonableness, and 3) necessity. *Oxford House, Inc. v. City of*

Baton Rouge, Louisiana, 932 F. Supp.2d 683 (M.D.La. 2013). The court found that the group home requested an accommodation from the city and it was refused. In its reasonableness inquiry, the court determined that no evidence existed that the proposed use was not sufficiently similar to the surrounding uses expressly permitted by the zoning code. Without such evidence, the court concluded that it would be more difficult to show that a waiver of the rule would cause a 'fundamental alteration' of the zoning scheme. Because the stated goal of the Oxford House was to create a supportive, family environment, no basis existed for the conclusion that the group home fundamentally altered the zoning scheme of the neighborhood. Thus, the requested accommodation was reasonable. Lastly, in order for the necessity requirement to be satisfied, two inquiries must be made: 1) whether the accommodation is necessary; and 2) whether the accommodation will afford equal opportunity to the disabled. In *Oxford*, the court determined that the accommodation was necessary because evidence showed that the type of group home living arrangement requested had an ameliorative effort on the residents' disability and the requested accommodation was necessary to afford equal opportunity.

The FHAA successfully defeated a defendant's effort to create additional hurdles for disabled renters to jump through. In *LaFlamme v. New Horizons, Inc.*, a severely disabled woman lived in a state-supported rental facility for people who were severely disabled yet able to live independently. When she returned from a hospital stay, she found that her apartment was no longer available. The defendants maintained that they should be allowed to draw distinctions based on the extent of their tenants' disabilities in order to serve the interests of all their residents by ensuring the viability of the facility. The disabled woman maintained that this practice, even if well-intentioned, was nevertheless disability discrimination and, therefore, violated the FHAA. The court concluded that the defendant's policy of leasing apartments only after inquiring into prospective tenants' medical and personal histories, and then assessing whether applicants are able to live independently based on the nature and characteristics of their individual disabilities, constituted exactly the kind of discrimination that the FHAA sought to forbid.

The FHAA has also succeeded in reducing the number of procedural burdens a city may impose on persons with disabilities. The court held, in *Easter Seal Society of New Jersey, Inc. v. Township of North Bergen*, 798 F.Supp. 228 (D.N.J. 1992), that certain notice and public hearing requirements, as well as a requirement that a conditional use permit be obtained, created a discriminatory impact. The requirements were, therefore, ruled invalid.

Residential organizations have also made it more difficult for persons with disabilities to live in community based housing due to fire and safety code restrictions. It is not unusual for a town to enact regulations to protect persons with disabilities which require their homes to have whole house sprinkler systems, fire retardant wall and floor coverings, lighted exit signs above all doors, fire extinguishers on the walls, and other safety features. These fire and safety regulations were found to violate the FHAA because they made it more difficult for persons with disabilities to live in the community of their choice. The City of Stow, Ohio, appealed the ruling of the court, but the Sixth Circuit Court supported the lower court and held that zoning ordinances are invalid if they treat people with disabilities differently from other individuals or from biological families (*Marbrunak v.*

City of Stow, 974 F.2d 43 (6th Cir. 1992)). The court stated that a city could have fire and safety regulations, but that the regulations had to be individually tailored to reflect the specific needs of the persons in question rather that assuming that all persons with developmental disabilities are at greater risk than other persons.

Regulations that limit the number of people who may live together have also been cited as violations of the FHAA, and they should be waived or modified to meet the reasonable accommodation requirement of the Act. (*Parish of Jefferson v. Allied Health Care, Inc*., 1992 WL 142574 (E.D.La. 1992). The FHAA states that discrimination occurs when a zoning board "refuses to make reasonable accommodations in rules, policies, practices or services when such accommodations may be necessary to afford such person equal opportunity to use and enjoy the dwelling." 42 U.S.C. Section 3604(f)(3)(B).

RECENT CASE LAW: *DeCambre* and *Texas Department of Housing*

Two recent cases shed new light on the nexus between housing and discrimination on the basis of disability. These cases are both a warning and a foreshadowing of future decisions. Parents and families of individuals with disabilities should be aware of these cases and how they could potentially impact their loved ones.

In *DeCambre v. Brookline Housing Authority* (D.Mass., No. 14-13425-WGY, March 25, 2015), a federal district court ruled that a local housing authority properly counted payments from a special needs trust as income when it determined that a Section 8 beneficiary was no longer eligible for a housing voucher. The plaintiff's SSI income, together with the distributions from her first-person trust, pushed her over the maximum income limits allowed for a Section 8 housing subsidy. In 2013, the Brookline Housing Authority informed her that she would no longer be eligible for Section 8 because the trust disbursed more than $60,000 to her for car, phone, internet, medical, dental, and veterinary expenses. After a hearing officer upheld the decision, the U.S. District Court for the District of Massachusetts ruled that the housing authority properly terminated her Section 8 benefits due to excess income.

On June 14, 2016, the First Circuit Appellate Court reversed the lower court's decision in *DeCambre*. In their opinion, the Appellate Court held that distributions of principal from a special needs trust should not be counted as income for purposes of Section 8 calculations. The court found that HUD income regulations exclude any "lump-sum additions to family assets," such as injury settlements. Based on its interpretation of these regulations, the First Circuit held that although investment income earned by trust assets and then distributed is countable, principal is not. Since the plaintiff in this case had no gain from her trust investments, there was no income to be counted. Brookline Housing Authority argued that the exclusion of "lump-sum additions to family assets" from income did not apply because the money was in a trust. The court rejected this assertion and found no support for such a position. As a result, the housing authority's decision that the plaintiff had too much income was reversed and her voucher was restored.

Even though the *DeCambre* case was, eventually, a significant victory for the disabled population, the case highlights the critical need for trustees of special needs trusts to stay well-informed about what government benefits the beneficiary is receiving. Familiarity with the income limits of eligibility requirements is critical as well. In hindsight, had the trustee known that Section 8 housing benefits would be in jeopardy due to excessive distributions, the trustee may have been able to avoid such an outcome. Here, the trustee learned the difficult lesson that Medicaid, SSI, and Section 8 do not all have the same income thresholds. The court did entertain the possibility that Congress would modify Section 8 rules, in light of the fact that special needs trusts were created to protect SSI and Medicaid. Until then, distributing from a special needs trust remains a trap for the unwary trustees whose beneficiaries are dependent on Section 8 housing. It is important to remember that distributions for medical or dental expenses are not deemed as income under Section 8 guidelines. It is paramount that a knowledgeable decision needs to be made to limit distributions from the trust to non-recurring, temporary, or sporadic payments.

In *Texas Department of Housing v. Inclusive Communities Project*, 135 S.Ct. 2507 (2015), the Supreme Court upheld the application of disparate impact claims under the Fair Housing Act. Disparate impact is a theory of liability that prohibits a party from using a facially neutral practice that has an unjustified adverse impact on members of a protected class, including race, gender, national origin, and disability. A facially neutral practice is one that does not appear to be discriminatory on its face, but is discriminatory in its application or effect. In *Texas Department of Housing*, the Inclusive Communities Project sued the administrator of low income housing tax credits. The tax credits are distributed to developers to create housing options for low-income individuals and families. The Project alleged that the tax credits were granted disproportionately to developments within minority neighborhoods and that the credits to developments within Caucasian neighborhoods were denied. The Project claimed that this practice led to concentrations of low-income housing in minority neighborhoods, which perpetuated segregation in violation of the Fair Housing Act.

The Court held that the Fair Housing Act focuses on the consequences of the actions in question rather than the actor's intent. Taking a comprehensive approach to interpreting the statute, the majority looked to companion legislation like Title VII of the Civil Rights Act and the Age Discrimination in Employment Act to find that those pieces of legislation contemplated disparate impact claims. This, together with the FHAA, strongly indicated to the majority that Congress acquiesced to this liability in the statute. The Court also found that disparate impact liability was consistent with the FHA's legislative purpose of preventing discriminatory housing practices and allowing plaintiffs to counteract unconscious prejudices and disguised discrimination that would be harder to reveal than disparate treatment. However, the Court emphasized the plaintiff's burden to establish robust causal connections between the challenged practice and the alleged disparities. Furthermore, a defendant's justification would not be held contrary to the disparate impact requirement unless it was artificial, arbitrary, and unnecessary.

Texas Department of Housing opens up the possibility of disparate impact litigation for individuals with disabilities. It is important to note that disparate impact claims do not require animus or hatred. The perpetrator of the facially neutral policy may harbor no ill will towards their constituents. However, the lack of animus is not a defense. The strength of disparate impact litigation is its power to combat hidden, unconscious, and disguised discrimination. Therefore, it is an important tool in the quiver of the fight to achieve fair and equal housing for persons with a disability.

APPENDIX B:

FREQUENTLY USED ESTATE PLANNING TERMS

Beneficiary -	The person who receives the “benefits” of a will, trust, life insurance policy, etc.
Codicil -	An amendment to a will which changes a portion of the will. A codicil must be signed and witnessed according to the same rules as the original will.
Guardian -	A person appointed by the court to assist a disabled person or a minor with his finances and/or personal decisions.
Grantor -	The creator of the trust; also known as a Settlor
Estate -	All of an individual's assets minus all of their debts at the time of death.
Estate Tax -	Currently (2016), federal estate taxes are due on estates over $5,430,000. With proper estate tax planning, a married couple can avoid paying federal taxes on a combined estate of up to $10.86 million dollars.
Executor -	The person who is responsible for carrying out the directions contained in a will. The executor usually works with an attorney to probate the estate with the court.
Heir -	A person who inherits property under state law
Inter vivos Trust -	A “living trust;” an instrument which comes into being during the lifetime of the Grantor or Settlor
Intestacy Laws -	Laws of a state which dictate how an estate will be distributed if a person dies without a will.
Irrevocable Trust -	A trust that cannot be changed by the maker of the trust once it has been executed. This type of trust is often used to avoid estate taxes because funds placed in the trust are generally not included in the creator's estate.
Probate -	A court procedure in which the assets of a deceased person are passed to beneficiaries under the provisions of a will or, if there is no will, under the state laws of intestacy.

Remainderman -	The person(s) who will receive the remainder of a trust after the initial beneficiary has died.
Revocable Trust -	A trust which can be revoked or amended during the life of the Grantor or according to the provisions included in the trust document. A revocable trust is generally included in the estate of the Grantor at the time of his death for purposes of determining estate taxes due, if any.
Special Needs Trust -	A trust used to provide supplemental care that is over and above what the beneficiary is able to obtain through his own earnings and/or through government benefits. A properly worded Special Needs Trust will not jeopardize government benefits which may, in fact, be more valuable than an inheritance.
Successor Executor -	The person who assumes the duties of Executor if the named executor dies or is unwilling or unable to perform their duties.
Successor Guardian -	The person who assumes the duty to handle finances and/or make decisions for a minor or disabled person if the named guardian dies or is unable or unwilling to perform their duties.
Testamentary Trust -	A Trust which goes into effect only upon the death of the Testator (the person making a will containing a trust). The trust will go into effect after the estate is probated.
Testator -	The person making a will.

APPENDIX C:

CASE EXAMPLES

Example 1: This example provides information on how three men with developmental disabilities were able to purchase a home of their own.

The three men, between the ages of 25-31, had been close friends for several years. All of them lived with their families, who helped them to obtain subsidized loans to purchase a home. All received SSI at the time and had jobs which provided them with additional income. The men were also eligible for Medicaid waiver funds through a local service provider. Each had his own guardian of the person at the time when the three initiated living together in a home of their own.

Once the men identified a home, they were able to obtain a mortgage for $40,000 from a local bank. This amount was derived from the combined incomes of each person of approximately $650 per month. In addition, they received a second mortgage from a federal housing program available to first time buyers who are low-income. This additional money brought their total available funds to $70,000. Because the purchase price of the home was $107,000, each of the three sets of parents contributed $12,000 towards the purchase price of the home.

The home is owned by the three men, but because they were under a guardianship at the time of the purchase they did not have the capacity to sign the loan papers for the mortgage themselves. The parents had to petition the court to expand the guardianship of the person to a guardianship of the estate and person. The parent also obtained permission from the court to sign the loan papers. Their parents, as guardians, signed on behalf of their respective ward, but were not personally liable for the loan. In order to protect the guardians from being personally liable, a court order had to be obtained authorizing them to sign the mortgage documents.

Each man now owns a one-third share of the home, which he is able to sell to another person if he no longer wishes to live in the home. Each month, a set amount of money is set aside into an escrow account for home repairs.

Example 2: This is another example of three men with developmental disabilities who were able to move into a home together. In this case, the home was gifted to a special needs trust for one of the young men.

The men, all of whom have physical challenges as well as developmental disabilities, had attended the same residential school together. All three aged out of their public school-funded placement in a private school at the same time, and were twenty-three years old when they decided to live together.

The parents of one of the three men owned a large home which was fully wheelchair accessible. The parents who owned the home created a special needs trust and gifted their home to the trust, naming their son as the beneficiary. The trustee then signed a rental contract with all three men, including the trust beneficiary, to live in the home. Neither of the two renters had a guardian, but it was recommended that each name an agent under a legal power of attorney for property to co-sign the rental agreement. This precaution was recommended to protect the trust in the event one of the two men ever violates the terms of the rental agreement and later claims he did not understand the rental terms.

The three men are all eligible for SSI, Medicaid, food stamps, fuel assistance and a CILA grant from the Illinois Department of Mental Health and Developmental Disabilities. The CILA grant pays the salary of a couple who moved into the home to assist the men in decision making and caring for their home. In addition, Medicaid pays for a personal care attendant who assists the men with their personal needs.

All three sets of parents are supplementing the care of their adult children through gifts and personal services. The parents of the two men renting from the trust were encouraged to establish a special needs trust for their sons, so, in the event of their deaths, the trust assets could provide the same supports to the men that the parents had provided during their lifetimes.

Example 3: This example provides information about a Section 8 subsidy that enabled a young woman with developmental disabilities to live in her own apartment.

The young woman's parents assisted her in applying for Medicaid, and food stamps; in addition she had income from her part time job at a grocery store and a Section 8 voucher. The woman was able to use the voucher to live in an apartment of her own near the store where she works. She visits her family often but enjoys the independence of living on her own. With minimal assistance from her mother and sister, she is able to budget her income on a monthly basis and handle all of her own finances. Upon her mother's death, she will continue to need minimal supervision in the area of money management. She is able to shop, clean her home, and schedule her own doctor's appointments independently, when needed.

The young woman participates as a volunteer staff person in a special recreation program sponsored by the local park district. In addition to her volunteer work, she keeps busy babysitting for her nieces and nephews and doing needlepoint. Although she has not yet made friends at work, nor become close to her neighbors, she states that she is happy and not lonely living alone. The young woman does not receive any assistance from the state agency serving persons with developmental disabilities, but does receive some state vocational and rehabilitation services. Her parents recently created a special needs trust which will protect their daughter's share of the inheritance they plan to leave for their three children. The parents are the co-trustees of the trust during their lifetimes and have named their other two children as successor co-trustees upon their deaths. The siblings know that they are to use the money to provide an advocate for their sister, if needed, and to provide her with financial assistance when necessary.

Example 4: This example concerns a man in his early thirties who recently received Medicaid waiver funds enabling him to move into his own apartment and hire individuals to assist him with developing the skills he needs to live alone.

The man located and rented his apartment with the assistance of his mother, who acts as his legal guardian of the person only and the representative payee for his SSI check. In addition to Medicaid and SSI, he receives food stamps.

The man's mother reports that since living alone, he has become much more capable of caring for his own needs. He is now able to wash his clothes, clean his home, and cook for himself. He still requires some assistance in making a grocery list and shopping, and has also not yet mastered the ability to handle his own money. His mother reports that he has received years of training in money management, and thus believes this is an area where he will always need assistance. He uses Medicaid waiver funds to hire a person to assist him in the areas for which he still requires assistance, such as in housekeeping, shopping and budgeting. Waiver funds were also used to pay a person to teach him how to use public transportation. He has an excellent sense of direction and he has become quite skilled in taking buses when he needs to get somewhere and cannot get a ride from his mother or a friend.

The man's mother is most concerned about her son's social life and participation in leisure activities. He does volunteer work for two community non-profit programs in the area, but has yet to meet a close friend. His mother has used waiver money to pay a person to be his companion/friend. She reports that these relationships have been disappointing due to the fact that her son has a severe speech impairment and has difficulty communicating with others. She is concerned about his social life, or lack thereof, and feels that this is the one area in which he is truly lacking fulfillment.

For the most part, however, she and her son are very pleased with the living situation. She says that thanks to the waiver funds, he now has choices about where he lives and has a say in hiring people to help him when he needs assistance.

APPENDIX D:

SELECTED BIBLIOGRAPHY

Abravanel, Evelyn Ginsberg, *Discretionary Support Trusts*, 68 Iowa L. Rev. 273 (1983).

Berkobien, Rick and Theresa Varnet, “Future Planning: Making Financial Arrangements with a Trust,” Available at: http://www.dsagno.org/old/library/article_pgs/fut_plan_art.htm.

Bogin, Matthew B., “Group Homes for Persons with Handicaps: Recent Developments in the Law,” 5 W. New Engl. L. Rev. 423 (1983), Available at: http://assets.wne.edu/159/29_arti_Group_Ho.pdf.

Cook, Timothy, “*Homeward Bound* Court Strikes Blow to State-Supported Segregated Services for Disabled Persons,” Mental and Physical Disability Law Reporter, Vol. 11, No. 5 (1987).

Cooper, Emily, Ann O’Hara, and Maura Collins Versluys. “Rural Housing Challenges: Meeting the Housing Needs of People with Disabilities in Rural Communities,” *Opening Doors: A Housing Publication For the Disability Community*. Issue 19(September 2002) Available at: http://www.tacinc.org/media/13740/Rural%20Housing%2019.pdf.

Cooper, Emily, Lauren Knott, Gina Schaak, Lisa Sloane, and Andrew Zovistoski, *Priced Out in 2014*, Technical Assistance Collaborative, Inc., June 2015, Available at: http://www.tacinc.org/media/52012/Priced%20Out%20in%202014.pdf.

Dadakis, John D. and Faith L. Carter, “Medicaid Eligibility and Trust Beneficiaries: The Benefits and Pitfalls of Multiple Beneficiaries,” ABA Trust & Investments 2011, available at: https://www.hklaw.com/files/Publication/62d7531b-56fb-4dee-9e2c-8f2b5d6dc6aa/Presentation/PublicationAttachment/b65a1e40-94f0-41a4-8dcc-925f6c84726b/TIND2011MedicaidEligibilityDadakisCarter.pdf

Elder Law Answers, “Medicaid’s Asset Transfer Rules: Know Who Can Give and Receive,” 2013, available at: http://www.elderlawanswers.com/downloads/guides/booklet-Medicaid-Asset-Transfer-Rules.pdf.

“Federal Housing Resource Guide,” The Technical Assistance Collaboration, Inc., 2012, Available at: http://www.tacinc.org/media/27844/Federal%20Housing%20Programs.pdf.

“Going It Alone: The Struggle to Expand Housing Opportunities For People With Disabilities,” The Technical Assistance Collaboration, Inc. (2000), Available at: http://www.tacinc.org/knowledge-resources/publications/reports/going-it-alone/.

Grassi, Jr. Sebastian V., “Estate Planning for a Family with a Special Needs Child,” *American Bar Association, Law Trends & News*, 2009, Available at: http://www.americanbar.org/newsletter/publications/law_trends_news_practice_area_e_newsletter_home/09_fall_ep_feat3.html.

Hardin, Jane, “Disability Advocacy Projects: Programs that Assist Low-income Clients and Ease State Governmental Fiscal Problems,” 26 Clearinghouse Review 776, Available at: http://heinonline.org/HOL/LandingPage?handle=hein.journals/clear26&div=107&id=&page=.

Herb, Marie and O’Hara, Ann, “HUD’s HOME Program: Can it Really Work for People With Disabilities?” *Opening Doors: A Housing Publication For The Disability Community* Issue 16, December 2001, Available at: http://www.tacinc.org/media/13600/HUD's%20Home%20Program%2016.pdf.

“Homeownership for People With Disabilities: A Movement in the Making,” *Opening Doors: A Housing Publication For The Disability Community*, Issue 6, December 1998, Available at: http://www.tacinc.org/knowledge-resources/publications/opening-doors/homeownership/.

Hoyt, Peggy R. and Candace Pollock, *Special People, Special Planning-Creating a Safe Legal Haven for Families with Special Needs* (Legacy Planning Partners, LLC, 2003).

“Influencing Affordable Housing Decisions In Your Community,” *Opening Doors: A Housing Publication For The Disability Community*, Issue 2, September 1997, Available at: http://www.tacinc.org/media/13626/Influencing%20Affordable%20Housing%202.pdf.

Jackins, Barbara, Richard Blank, et.al., Special Needs Trust Administration Manual: A Guide for Trustees, (iUniverse, Inc., 2005).

Johnson, Holly, “Home Ownership for People with Disabilities,” February, 1, 2016, available at: http://www.thesimpledollar.com/home-ownership-for-people-with-disabilities/.

Karaim, Reed, People with Physical Disabilities,@ *Housing First: A Special Report*http://www.npr.org/news/specials/housingfirst/whoneeds/physdisabled.html.

Kefalas Dudek, Patricia E. and Martha A. Churchill, “Adults with Disabilities: Prepare for the Future with a Special Needs Trust”. Vol. 79 Michigan Bar Journal, (October, 2000), Available at: http://www.pekdadvocacy.com/documents/pattispublications/Estate/AdultsWithDisabilities-PrepareWithSNT.pdf.

Kotkin, Minna J., “The Fair Housing Amendments Act of 1988: New Strategies for New Procedures,” 17 N.Y.U. Journal of Law and Social Change, 755 (1989-1990), Available at: http://brooklynworks.brooklaw.edu/cgi/viewcontent.cgi?article=1322&context=faculty

Krouk-Gordon, Dafna and Barbara D. Jackins, *Moving Out: A Family Guide to Residential Planning for Adults with Disabilities* (Woodbine House, 2013).

Lee, Jacqueline "Suburb Sued for Unfair Zoning; Justice Department, Group Homes Using New Law for Disabled," Vol. 75 ABA Journal 40 (September 1989), Available at: https://books.google.com/books?id=NH7bPpTiA38C&pg=PA40&lpg=PA40&dq=Suburb+Sued+for+Unfair+Zoning;+Justice+Department,+Group+Homes+Using+New+Law+for+Disabled&source=bl&ots=jaioDzq6d5&sig=wv2xEktXq77t4Sv6eMjKkluKs2k&hl=en&sa=X&ved=0ahUKEwiloaGRms3MAhXIbD4KHQ7kChgQ6AEIHTAA#v=onepage&q=Suburb%20Sued%20for%20Unfair%20Zoning%3B%20Justice%20Department%2C%20Group%20Homes%20Using%20New%20Law%20for%20Disabled&f=false.

Levy, Richard E., "Social Security Claimants with Developmental Disabilities: Problems of Policy and Practice," Vol. 39 University of Kansas Law Review 529 (Spring 1991), Available at: https://kuscholarworks.ku.edu/bitstream/handle/1808/955/Richard%20E.%20Levy%2c%20Social%20Security%20Claimants%20with%20Developmental%20Disabilitites%20-%20Problems%20of%20Policy%20and%20Practice%2c%2039%20U.%20Kan.%20L.%20Rev.%20529%20%281990-1991%29.pdf?sequence=1&isAllowed=y

Marsocci, Jeffrey G., *The Simple Guide to Special Needs Estate Planning: Special Needs Estate Planning Explained in Plain English* (Domestic Partner Publishing, LLC, 2012).

Maccaro, James A., "An Outline of Social Security Disability Law," Vol. 85 Massachusetts Law Review 106 (Winter 2001), Available at: http://heinonline.org/HOL/LandingPage?handle=hein.barjournals/malr0085&div=15&id=&page=

Miller, Richard P., "Funding Living Trusts: An Overview and Introduction," Vol. 89 Illinois Bar Journal. 628 (December 2001).

Mitchell, Brent A., "Medicaid Planning for the Elderly: Using Supplemental Discretionary Trusts to Pay the Costs of Long-Term Care," Vol. 31 Washburn Law Journal 80 (Fall 1991), Available at: http://heinonline.org/HOL/LandingPage?handle=hein.journals/wasbur31&div=11&id=&page=.

Mooney, Carol Ann, "Discretionary Trusts: An Estate Plan to Supplement Public Assistance for Disabled Persons," Vol. 25 Arizona Law Review 949 (Fall 1983), Available at: http://heinonline.org/HOL/LandingPage?handle=hein.journals/arz25&div=31&id=&page=

Nadworny, John W. and Cynthia Haddad, *The Special Needs Planning Guide: How to Prepare for Every State of Your Child's Life* (Brookes Publishing, 2007).

National Academy of Elder Law Attorneys, “Myths and Realities About Medicaid Planning,” June 25, 2014, available at: https://www.naela.org/NAELADocs/PDF/Advocacy%20Tab/GAOMythsReality06_24_14.pdf.
O’Hara, Ann, “Permanent Supportive Housing: A Proven Solution to Homelessness,” *Opening Doors: A Housing Publication For The Disability Community*, Issue 20, January 2003, Available at: http://www.tacinc.org/media/13714/PSH%2020.pdf.

O’Sullivan, Timothy P. and Kent A. Meyerhoff, “Drafting Support and Discretionary Trusts: Navigating the Perils and Possibilities,” Kansas Bar Association and Wichita Bar Association, 2012, available at: www.foulston.com/News/PDF/575.

Olivas, Luana, “Helping Them Rest in Peace: Confronting the Hidden Crisis Facing Aging Parents of Disabled Children,” Vol. 10 Illinois Elder Law Journal Fall 2002, Available at: http://publish.illinois.edu/elderlawjournal/files/2015/02/Olivas.pdf.

Pepper, Beth, “Highlights in Fair Housing Law: Strengthening the Rights of People with Disabilities to Live in the Community of their Choice,” Vol. 26 Clearinghouse Review 1458 (March 1993), Available at: http://heinonline.org/HOL/LandingPage?handle=hein.journals/clear26&div=174&id=&page=

Perlstein, Abraham J., “Comprehensive Future Care Planning for Disabled Beneficiaries,” Vol. 27 Estate Planning. 358 (October 2000).

“Pooled Trust Programs for People with Disabilities: A Guide for Families,” The Arc of the United States, 2002, Available at: http://www.arc-wisconsin.org/media/70510/pooledtrustprogramsguide1.pdf.

Roscher, Webber Barton, “Providing for Adult Children with Disabilities in a Traditional Estate Plan: Looking Beyond the Special Needs Trust,” *Probate & Property Magazine: Volume 27, No. 06*, November/December 2013, available at: http://www.americanbar.org/publications/probate_property_magazine_2012/2013/november_december_2013/2013_aba_rpte_pp_v27_6_article_roscher_adult_children_with_disabilities.html.

Rounds, Charles E., Jr. and Charles E. Rounds, III, *Loring and Rounds: A Trustee’s Handbook* (Wolters Kluwer Law and Business, 2015).

“Securing A Future for Your Child with a Disability,” The Arc of Northern Virginia, January 2014, Available at: https://www.alexandriava.gov/uploadedFiles/dchs/childrenfamily/WaiverProgramsGuideforParents.pdf

Seligmann, Terry Jean, “Not As Simple As ABC: Disciplining Children with Disabilities Under the 1997 IDEA Amendments,” Vol. 42 Arizona Law Review 77 (2000), Available at: https://litigation-essentials.lexisnexis.com/webcd/app?action=DocumentDisplay&crawlid=1&doctype=cite&docid=42+Ariz.+L.+Rev.+77&srctype=smi&srcid=3B15&key=c7c9d3463ca9e8a5f3fae2acf2391884.

Shalloway, Mark G., “Selecting and Advising Trustees of Special Needs Trusts,” Vol. 15 NAELA Quarterly 16 (Spring 2002), Available at: http://jay.law.ou.edu/faculty/KGuzman/Advanced%20Trusts/Fall%202010/Handout%204A.pdf.

Simpson, Jim, “Law for the Intellectually Handicapped: A Continuing Unmet Need,” Vol. 9 Legal Service Bulletin 220 (October 1984), Available at: http://heinonline.org/HOL/LandingPage?handle=hein.journals/alterlj9&div=67&id=&page=.

Simring, Richard B., “The Impact of Federal Antidiscrimination Laws on Housing for People with Mental Disabilities,” Vol. 59 George Washington Law Review, 413 (January 1991), Available at: https://litigation-essentials.lexisnexis.com/webcd/app?action=DocumentDisplay&crawlid=1&doctype=cite&docid=59+Geo.+Wash.+L.+Rev.+413&srctype=smi&srcid=3B15&key=3de23fa65158ce07667362132fa6aa02.

Special Needs Alliance, “Administering a Special Needs Trust: A Handbook for Trustees,” 2016 Edition, available at: http://www.specialneedsalliance.org/wp-content/uploads/2016/04/2016-Handbook-for-Trustees.pdf.

“The Housing Timebomb: The Housing Crisis Facing People With A Learning Disability and Their Older Parents,” MENCAP, (June 2002), Available at: https://www.mencap.org.uk/sites/default/files/documents/Housing%20Timebomb.pdf.

Tebo Graham, Margaret, “Which Way for the ADA?” Vol. 86, No. 12 ABA Journal (December 2000), Available at: http://www.jstor.org/stable/27841200?seq=1#page_scan_tab_contents.

Turnbull, Rutherford H., III, et. al., *Disability and the Family: A Guide to Decisions for Adulthood*, Paul H. Brooks Publishing Company, 1989.

United Spinal Association, “Understanding the Fair Housing Amendments Act: A Publication of United Spinal Association,” 2004, available at: https://www.unitedspinal.org/pdf/fair_housing_amendment.pdf.

Urbatsch, Kevin and Michele Fuller, *Special Needs Trusts: Protect Your Child’s Financial Future*, 6th Edition (NOLO Press, 2015).

Varnet, Theresa M., M.S.W., J.D., Future Financial Planning, *The Exceptional Parent* November/December, 1988.

Varnet, Theresa M., M.S.W., J.D., Creating Housing Choices for Disabled Beneficiaries by the Use of Supplemental Needs Trusts,@ NAELA Quarterly, (Summer, 2002).

Varnet, Theresa M., M.S.W., J.D., qtd. in “How to Plan a Secure Future for Children with Mental Handicaps,” *Kiplinger’s Personal Finance*, April 1, 2000.

qtd. in “Providing for a Person with Special Needs,” *Kiplinger’s Retirement Report*, November, 2000.

qtd. in “Caring for Those in Need: Make Sure Your Disabled Heirs Get the Treatment They Deserve,” *Town & Country*, August, 2002.

“What ‘Fair Housing’ Means for People with Disabilities,” The Judge David L. Bazelon Center for Mental Health Law, April, 2011, Available at: http://www.bazelon.org/LinkClick.aspx?fileticket=bdk6FSfUBOQ%3D&tabid=104.

Weinberg, Diane, “Common Pitfalls When Planning Estates for Families with Special Needs Children,” November 2012, available at: http://morgandisalvo.com/wp-content/uploads/2012/11/November-2012-Newsletter-Common-Pitfalls-When-Planning-Estates-for-Families-with-Special-Needs-Children.pdf.

Wirth, Richard J., “Clearing the Way for Handicapped Individuals in Common Interest Communities,” Vol. 21 Real Estate Law Journal 152 (Fall 1992).

Wright, Hal, *The Complete Guide to Creating a Special Needs Life Plan: A Comprehensive Approach Integrating Life, Resource, Financial, and Legal Planning to Ensure a Brighter Future for a Person with a Disability* (Jessica Kingsley Publishers, 2013).

APPENDIX E:

ADDITIONAL RESOURCES

For additional information, contact the following organizations:

American Network of Community Options and Resources
1101 King Street, Suite 380
Alexandria, VA 22314
tel.: 703-535-7850
www.ancor.org

The Arc of the United States
1825 K Street, NW, Suite 1200
Washington, DC 20006
tel.: 800-433-5255
www.thearc.org

Association for Children with Down Syndrome
4 Fern Place
Plainview, NY 11803
tel.: 516-933-4700
fax: 516-933-9524
email: info@acds.org
www.acds.org

Beach Center on Families and Disabilities, Bureau of Child Research,
The University of Kansas
Haworth Hall, Room 3136
1200 Sunnyside Ave.
Lawrence, Kansas 66045
tel.: 785-864-7600/866-783-3378
fax: 786-864-7605
email: beachcenter@ku.edu
www.beachcenter.org

- The Beach Center offers a publications catalog and newsletter. The website includes articles on Person Centered Planning.

FDIC Headquarters:
550 17th St. NW
Washington, DC 20429
tel.: 877-275-3342
www.fdic.gov
www.fdic.gov/buying/owned/index.html - FDIC real estate home

Center for Parent Information and Resources
c/o Statewide Parent Advocacy Network
35 Halsey St., Fourth Floor
Newark, NJ 07102
email: malizo@spannj.org
www.parentcenterhub.org

Consortium for Citizens with Disabilities
1825 K Street, NW, Ste. 1200
Washington, DC 2006
tel.: 202-783-2229
fax: 202-534-3731
email: info@c-c-d.org
www.c-c-d.org

PACER Center
8161 Normandale Blvd.
Bloomington, Minnesota 55437
tel.: 952-838-9000/800-537-2237
fax: 952-838-0199
www.pacer.org

- The mission of PACER Center is to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families, based on the concept of parents helping parents.

Parent Educational Advocacy Training Center (PEATC)
8003 Forbes Place, Suite 310
Springfield, VA 22151
tel.: 703-923-0010
email: partners@peatc.org
www.peatc.org

- PEATC provides information and training to parents, professionals and students with disabilities. PEATC also has a publication list and quarterly newsletter, PEATC Press.

Parents Helping Parents
Sobrato Center for Nonprofits-San Jose
1400 Parkmoor Ave., Suite 100
San Jose, CA 95126
tel.: 408-727-5775/855-727-5775
fax: 408-286-1116
www.php.com

Technical Assistance Collaboration
31 St. James Ave., Suite 950
Boston, MA 02116
tel.: 617-266-5657
www.tacinc.org

U.S. Department of Housing and Urban Development
451 7th Street SW
Washington, DC 20410
tel.: 202-708-1112
http://portal.hud.gov/hudportal/HUD

APPENDIX F:

SELECTED WEBSITES ON HOUSING
(Compiled by the Center for Housing and New Community Economics)

Institute on Disability/New Hampshire's University Center for Excellence in Disability
http://www.iod.unh.edu/Home.aspx

The Corporation for Enterprise Development
www.cfed.org

The Center on Human Policy (CHP)
http://thechp.syr.edu/

The Center for Social Development (CSD)
http://gwbweb.wustl.edu/csd

The National Council of State Housing Agencies (NCSHA)
www.ncsha.org

The Center for Universal Design
http://www.ncsu.edu/www/ncsu/design/sod5/cud/

The National Low-Income Housing Coalition/LIHIS
www.nlihc.org

Fannie Mae's HomeChoice mortgages
www.FannieMae.com

The National Coalition of the Homeless
www.nationalhomeless.org

Bazelon Center for Mental Health Law
http://bazelon.org

United States Department of Agriculture
Rural Development
www.rurdev.usda.gov

NOTE: This list is by no means a comprehensive list of web sites with valuable information on housing. Please use the links on each of these web sites to further explore many other useful sites on housing.

APPENDIX G:

SAMPLE HOUSING BUDGET

EXPENSES (Total to be divided by 3)		**INCOME** (per individual)
	Per Year	
HOUSING		
Rent	$14,400	$5,352 ($446/month SSI)
Insurance	$90	$0
Heat	$600	$0
Maintenance	$1,800	$0
Telephone	$240	$0
Electricity	$660	$0
CONSUMABLES		
Food	$4,500	$1,380 (Food Stamps)
Non-Food Supplies	$900	$0
Clothing	$3,000	$0
Hygiene Supplies	$360	$0
Recreation/Leisure	$2,160	$0

ANNUAL BUDGET FOR THREE INDIVIDUALS WITH SEVERE DISABILITIES LIVING IN A SHARED APARTMENT

Cont'd.

TRANSPORTATION		
Vehicle	$6,000	$516 (Paratransit for elderly and disabled)
Fuel	$1,600	
Insurance	$1,400	
STAFFING		
Direct Care and Support Staff	$76,920	$7,248 (Total income per person)
FICA & Benefits (21%)	$16,153	$41,741 (Amount needed from trust or other State/federal programs)
Administrative Overhead (.07%)	$5,384	
ADVOCATE / PEER / COMPANION	$10,800	
TOTAL YEARLY BUDGET	$146,967	
Per Person	$48,989	$48,989