

Financial and Estate Planning for Persons with Disabilities, Elders and their Families

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I. Anticipating Future Needs For Clients and Their Family Members

A. Introduction

The quality of life of people with disabilities, elders and their families is often in direct proportion to their level of planning. Our role is to provide customized tools and solutions which not only protect their present quality of life, but reflect their dreams and adapt to changing needs.

To provide those solutions, we must anticipate the unique medical care, long-term care and financial management needs of the client. This goes beyond traditional estate planning tasks and involves a multi-disciplinary approach to our plans of action.

- It means understanding the present and possible future “stages” of the client’s condition and the operative issues in each of those stages.
- It entails reviewing the family dynamics and roles on issues as caregiving, medical decisions and financial management.
- It means familiarity with the medical and long-term care systems applying to that type of illness, frailty or disability.

Often it is necessary to team with other professionals as the social worker, geriatrician, case manager and financial planner. See Mary L. Pannen, “A Win-Win Partnership: The Elder Law Attorney and Geriatric Care Manager,” 13 *NAELA Quarterly* 25 (Spring 2000).

Although each particular condition has different issues and traps for the unwary, there are groupings of disabilities and illness with common needs and concerns. For purposes of this outline, I have grouped disabilities into four areas:

1. Developmental Disability;
2. Adult-onset disability, consisting of chronic illness capable of rehabilitation and/or stabilization;
3. Adult-onset disability, consisting of chronic degenerative illness; and
4. End-stage terminal illness.

The first half of this outline treats some of the **needs** an elder law, special needs and disability attorney should anticipate on medical care, long-term care and financial management for each of these groupings.

The second half of this outline concentrates on some effective **planning** measures for such groupings as to both anticipated and unexpected needs. I differentiate between preventative planning measures and responsive planning measures.

B. Developmental Disability – a Functional Definition

Depending on the system, there are various definitions of “developmental disability.” Eligibility and priority for services under state and federal programs depend on fitting criteria for developmental disability or children’s disability.

The 1996 revisions to the Michigan Mental Health Code set criteria based on *functional* need, instead of a set diagnosis. For children older than 5 years, the Code requires a severe chronic condition, which:

1. relates to a mental and/or physical impairment;
2. occurs before age 22;
3. is likely to continue indefinitely;
4. results in substantial functional limitations in 3 or more of the following areas of major life activity: self care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency; and
5. reflects the individual’s need for combinations of special care and services which will be lifelong or of extended duration and individually planned and coordinated.

MCLA 330.1100a(20)(a) (*paraphrased*).

For children from birth to 5 years, the definition allows preventative intervention. It is sufficient for there to be a substantial developmental delay or specific congenital condition with a “high probability” of developmental disability. MCLA 330.1100(a)(20)(b).

Eligibility for specialized care or benefits under certain state programs and federal may not have as flexible of definition, depending on set diagnoses and severity of need, as discussed below. For a critique of such definitions under Michigan’s DD managed care program, *see Response Paper*, The Arc Michigan, Michigan Department of Community Health, DD Carve Out Concept Paper and Call for Comments, February 19, 1997.

C. Anticipating Medical Needs with Developmental Disability

A primary concern of parents with a child with a developmental disability involves assuring the proper level of care for their child both during their lifetime and in the event of their own disability or death.

1. Obtaining Specialty Medical Care. Parents must hurdle many difficult tasks to obtain the specialty medical care necessary for their child with a disability. Specialized assessments, treatments and plans of care are necessary to develop. No uniform procedure exists for particular disabilities. Much of the care is dependent on coordinating private health insurance, Medicare, Medicaid and other programs of federal and state assistance.

Recent changes to Michigan’s public health system, especially in managed care, have increased the responsibility of family members to coordinate medical services, especially long-term care. Parent support groups through community organizations as the Arc of Michigan, the Alliance for the Mentally Ill and the United Cerebral Palsy Association can provide key information and advocacy.

A statewide system of local community mental health organizations are charged by the Mental Health Code to provide a “person centered approach” to planning, selection and delivery of supports in the public mental health system. These organizations contract with the Department of Community Health under the State Medicaid managed care and fee-for-service programs. An

individualized plan is developed for service, supports and/or treatment. Families have a right to be present at such professional assessments and use the program as a resource for systems of ongoing support.

In addition, the Michigan Department of Community Health offers support services for families through its “Children’s Special Health Care Services (CSHCS) Plan Division.” The CSHCS assists with coordinating specialty services and coverage for eligible children from birth to age 21. Approximately 27,000 children are currently enrolled in its program. Children qualify based on a list of 2,700 medical diagnoses and factors as severity, chronicity and need for a physician specialist. This program serves both Medicaid and non-Medicaid eligible children.

Special health plans under CSHCS cover specialty care and treatment relating to qualifying diagnoses. Two private health insurance organizations “Kids Care of Michigan” and “Children’s Choice of Michigan” have contracted with CSHCS to provide statewide coverage.

Other benefits under CHSCS include coordination of other insurance benefits, transportation for services, access to specialists and linkage with other community resources.

2. Coordinating Care through Special Education. Integral to the medical care of the child is the evaluation and development of an *individualized educational program (IEP)*. Key federal legislation with the Individuals with Disabilities Education Act (IDEA) mandates that children from three to twenty-one receive special education and “related services.” 20 USC §1401(d),1411(a). Related services include speech, physical and occupational therapy, audiology, rehabilitation counseling and psychological services. 20 USC §1402(22).

Extensive administrative regulations under the Michigan Mandatory Special Education Act complement IDEA in mandating special protections of the plan. MCLA §380.1711; 380.1751. Michigan stands as the only state extending the period of special educational services up to age 26. The extended length of the program, however, is under scrutiny. See “Executive Editorial,” *The Arc Michigan Focus* (Spring 2001).

A multi-disciplinary evaluation team evaluates the child and each year the written plan document is reviewed and updated. Disputes between parents and school personnel may not only arise over educational programs, but the provision of the “related services.” Mediation of these disputes has been encouraged by Congress in 1997 amendments to IDEA. See Laura A. Athens, “Special Protections for Students with Disabilities,” *Laches*, 13-17, Oakland County Bar Assoc. (February 2001).

An important task also protected by IDEA and other federal statutes is obtaining the necessary *assistive technology*. IDEA mandates that schools provide “assistive technology devices” which “increase, maintain or improve functional capabilities of individuals with disabilities.” 20 USC §1401(a)(25); 34 CFR 300.5. CSHSC has a special trust fund to help families obtain wheelchairs and assistive technology.

As the child matures, beginning at no later than age 16 (and in some cases 14 or younger), the IEP must include a plan for “transition services” the student will need when leaving the school setting. 34 CFR 300.347(b)(2). This not only includes assessment for vocational training, but the functional evaluation for transitions to independent living and daily living skills. 34 CFR 300.18(a).

3. Pursuing Alternatives to DD Guardianship. When the child turns 18, the parents no longer are recognized as the legal guardians. In the last twenty years, a strong trend has existed against the categorical removal of rights through the establishment of a developmental disability (“DD”)

guardianship. Such guardianships have been inappropriately encouraged by school and agency personnel either through misunderstandings or for the convenience of the providers. See “Resolution Regarding Guardianship for People with Developmental Disabilities” (December 5, 1992), The Arc Michigan, in *Planning a More Secure Future*, 4th ed., Thomas F. Kendzierski (1995).

If necessary, the DD guardianship require specialized assessments evaluating psychological, physical, social and educational condition, adaptive behavior and social skills. MCLA 330.1612(1)(b). A physician or psychologist must participate in the report and recommendations about the most appropriate rehabilitation plans and living arrangements. MCLA 330.1612(1)(d)(E). Partial guardianships are encouraged and the duration is only five years. MCLA 330.1626(2).

See Section II. H. below, “Estate Planning for Developmental Disability” for the special needs trust and other alternatives to guardianship.

D. Anticipating Long-term Care Needs with Developmental Disability

1. In General. An often equal concern to specialty medical care is the housing arrangement for their child, especially in the event of the caregiver’s disability or death. Governmental benefits as SSI provide very limited income for adequate housing. According to The Arc – United States, people with developmental disabilities often live well into their 60’s and nearly a half million adults are living with a parent who is over 60. See Susan Garland, “When Your Kids Will Always Be Dependent,” *Business Week* 233 (April 10, 2000).

The following questions often arise:

- How do we avoid institutional care?
- What home and community based care options exist?
- Will my own home or a private home be available for housing?

2. “The Least Restrictive Setting”. The key task parents face is ensuring the most appropriate and least restrictive setting. A strong trend in the past twenty five years for people with developmental disabilities has existed to close state institutions in favor of community living arrangements. In 1967 there were 12,694 individuals with developmental disabilities residing in public institutions, in 1998 this decreased to 282. See Michigan Community Mental Health website at <http://www.mdmh.state.mi.us>.

Recently Minnesota became the tenth state/district to close all of its state institutions for people with developmental disabilities. The Arc Oakland County, *24 Profiles* 2 (Feb.-Mar. 2001).

The government trend is for placement in residential settings of six or fewer persons. According to a 1998 survey, 89% of persons with developmental disabilities in Michigan now live in residential settings of six or fewer persons, consisting of group homes (43%), private intermediate care facilities (24%), supportive living arrangements (19%) and foster care (13%). Ten years earlier, only 49% of persons lived in residential settings. Most of the other half of persons were institutionalized in nursing homes and state institutions (43%). See D. Braddock, *et. al.*, “The State of the States in Developmental Disabilities: 2000,” at <http://www.uic.edu/depts/idhd/stateofthestates/michigan/htm>.

The United States Supreme Court recently bolstered the trend against institutionalization in favor of care in the most appropriate integrated setting. *Olmstead v. LC*, 119 S.Ct. 2176 (1999). The Court affirmed that unjustified segregation and institutionalization of persons with

disabilities by the state is unlawful discrimination under the Americans with Disabilities Act (ADA).

A more recent case before the U.S. Supreme Court threatened the constitutionality of the enforcement provisions of the ADA against state governments under the Eleventh Amendment. Board of Trustees of the University of Alabama v. Garrett, No. 99-1240 (Feb. 21, 2001). Individuals can no longer sue states for damages for discrimination on the basis of disability in employment under Title I of the ADA. However, this decision does not affect injunctive relief against states. Lawsuits for damages and injunctive relief still remain against local and quasi-governmental organizations. Finally, the court explicitly limited its decision to state *employment* practices.

Part of the trend against institutionalization and in favor of residential care in the “least restrictive setting” has been the development of the home and community based waiver services. Michigan has a series of waiver programs each administered through the community mental health system. Each program provides a range of home based therapies treatments and support services. See Patricia E. Kefalas Dudek, “Home and Community Based Waiver Programs From A to Z,” *ICLE 2001 Medicaid and Health Care Planning Update* (February 2001).

D. Anticipating Financial Management Needs for Developmental Disability

1. Addressing Adequate Planning. A study by the University of Maryland examined the degree of residential, financial and estate planning of mothers (mean age 67) with adult offspring who have suffered with long-term mental illness. Of the 157 mothers surveyed, the results showed:

- Only 11% had definite plans for their child’s future residence and many had done little or no residential planning;
- Three-quarters hoped another family member would assume care, yet only one-quarter thought such arrangements would definitely occur; and
- Although two-thirds expressed the need for services to assist with financial and estate planning, less than one-third had used such services.

See G. Smith, *et. al.*, “Planning by Older Mothers for the Future Care of Offspring with Serious Mental Illness,” 51 *Psychiatric Services* 1162-66 (Sept. 2000).

2. Confronting Essential Questions on Housing and Care. Attorneys can help parents confront difficult financial issues on housing and care as:

- How much is enough for the housing need and a meaningful lifestyle? Housing and transportation require cash. Mortgages and financing generally are not possible for people with disabilities.
- Is life insurance the best route to provide the cash needs?
- If the disability is not severe, will my child be functional enough to earn a living?
- Will my child be able to secure and maintain health insurance, especially when my group benefit coverage terminates?
- Are the poverty programs of SSI and Medicaid necessary if we have functioned without them?
- How do we obtain Social Security Disability (SSDI)?

- Will Medicare (available after twenty four months of SSDI) and Medicare Supplemental Insurance be sufficient?
- Who should manage the assets for the benefit of the child after my death?
- How should I weight the inheritance with my other children?
- How do I involve my other children in the management of care? How do I compensate them for the task?
- When is a special needs trust necessary? How is the trust managed? Are the assets enough to justify a corporate trustee?

E. Chronic Illness Capable of Rehabilitation/Stabilization – Defined

Of the 49 million Americans with disabilities, the majority live with some form of adult-onset disability. Of these adult-onset disabilities, there are two forms: those capable of *rehabilitation/stabilization* and those which are *degenerative*.

This section focuses on the type of chronic illness which is capable of rehabilitation and/or stabilization. The events leading to the disability could be a trauma as a hip fracture, a stroke or surgical procedure resulting in serious complications. I also treat within this section the special considerations involving persons with mental illness in stabilizing their condition.

F. Anticipating Medical Needs for Rehabilitative Chronic Illness

1. Navigating the Medicare Hospital Admission and Discharge Process. Here the person and caregivers focus on improving functioning and management of the illness through skilled therapies. Often there is a hospital admission, followed by a program of therapy either in a sub-acute facility, in a rehabilitation center or in the home.

Generally the primary task is advocating for coverage of the necessary medical therapies by Medicare and health insurance, especially on the duration of coverage. Medicare and health insurance plans limit the days of hospital coverage for every covered illness (called diagnostic related groups or “DRGs”). Because of this, the hospital discharge planner or “care coordinator” may need to pressure family members shortly after admission to identify alternative placement.

Hospital systems have developed their own extensions – in the form of sub-acute, rehabilitative, skilled nursing, home care and roving therapy systems – to continue to capture the patient’s Medicare and health insurance dollars. The Health Care and Financing Administration (“HCFA”) and private health insurance providers have attempted to contain the costs, investigating fraud and producing incentives to discontinue therapies.

In the blur of the events and often at a critical point of recovery, the patient and family members may find themselves in placements and programs without much specific information on their options and the effects of their choices. Medicare discharge planning advocacy has become increasingly necessary.

2. Medicare Discharge Advocacy. Discharge planning advocacy occurs in these areas :

- The determination of the medical necessity of continued hospitalization;
- The assessment of the patient’s need for skilled nursing care;
- Screening which occurs in the skilled nursing facility (SNF) admissions based on the amount of finances and potential need for Medicaid; and

- Obtaining payment by the Medicare+Choice organizations (managed care Medicare which the patient “opted” into after a free breakfast).

Example: It took months for my client to receive the Medicare hospital and nursing home payment from a California Medicare+Choice organization for a California relative who was hospitalized and admitted to a Michigan nursing home, who subsequently died.

See 42 USC §1395(ee); 42 CFR §482.43 (Hospital Discharge Planning);

See also Center for Medicare Advocacy, “Medicare Discharge Planning Advocacy,” 1 *Healthcare Rights Review* 1-5 (January 2001).

3. Special Hospital Discharge and Medical Coverage Advocacy for Mental Illness. For persons hospitalized for mental illness, they too may find themselves in a short hospital stay, followed by a transition period of out-patient treatment. Similar discharge and coverage planning occurs with Medicare Part B and health insurance plans for “reasonable and necessary” outpatient psychiatric services. Managed care health plans must certify whether the mental health care is “medically necessary.” Again, the need for advocacy on coverage becomes crucial.

G. Anticipating Long-term Care Needs for Rehabilitative Chronic Illness

1. Finding a Medicaid Certified Bed. Once in the rehabilitative center or skilled nursing facility (SNF), the golden days of Medicare long-term care are numbered. At times the hundred day Medicare coverage period is cut short because the patient is no longer improving in therapy. Prior to that determination, a family may receive warning signals in the care conferences they may attend which are mandated by Medicare regulations. When adequate warning is not given, an appeal of the determination may be appropriate.

During the period of Medicare coverage, the family should be planning for the next segment of care. It seems increasingly difficult to find Medicaid-certified beds within the same SNF, especially for the SNFs owned by certain hospital chains. If continued nursing care is necessary and a Medicaid spend down is probable, the move should be carefully planned. While the Medicare coverage still exists families may use the Medicare “ticket” to gain admission to a nicer Medicare/Medicaid facility than otherwise would be available on a pure private pay status. Financial screening, although contrary to Medicare regulations, is the norm.

2. Maintaining Home Health Care. For Medicare home health care the focus is keeping the home health services in place. Effective October 1, 2000, Medicare implemented a prospective payment system (PPS) to pay for home health care. Instead of open billing by home health agencies, HCFA determines in advance how much it will pay for services for each 60 day episode of care. Advocates should be alert to patients being discharged sicker and quicker. See Healthcare Financing Administration, *Home Health Care: Improving Quality, Tightening Standards* 2 (Aug. 8, 1997) at <http://www.hcfa.gov/facts/f970808.htm>.

It is primarily at the point when Medicare is no longer available that most long-term care insurance, if existing with the client, becomes effective.

3. Home and Community Based Waiver Programs. Just like in the DD setting, Medicaid home and community based waiver services exist for elders and adults with disabilities who live at home but who without such assistance would require nursing home care. Clients who apply for the limited number of slots must meet the same medical criteria and asset restrictions as nursing home Medicaid. Poor coordination and limited agency services have weakened this program.

4. Mental Illness – Special Considerations for Long-term Care. The key task for the family is to attempt to prevent the revolving door of hospitalizations and discharge. Like the developmental disability setting, the movement has been away from institutionalization to residential options in the “least restrictive setting.” The number of persons in psychiatric hospitals has decreased from close to 20,000 in 1960 to 1,244 in 1988. See <http://www.mdmh.state.mi.us>.

For older persons suffering from mental illness, community mental health workers are required to screen the appropriateness of any nursing home placement under federal Medicare and Medicaid regulations. 42 CFR 483. While dementia is a recognized form of disability for admission to a nursing home, mental illness and mental retardation are forms of illness the community mental health worker must screen out for more appropriate placements. Id.

The Michigan Department of Community Health has contracted with community care organizations as part of its Medicaid managed care efforts to assist adults with disabilities as mental illness to live in residential settings.

H. Anticipating Financial Needs for Rehabilitative Chronic Illness

1. Assessing Medical Coverage. One primary financial issue for persons and families with this type of chronic illness is ensuring medical coverage by the relevant insurance provider. If the person is younger, and not participating with Medicare, then continued coverage by health insurance becomes a key issue if the person is no longer employable. See “Insurance” below.

2. Assessing Rehabilitative Potential and Employment. Another crucial financial issue is ascertaining the degree of rehabilitative potential. Important questions are:

- Will the person be able to return to work?
- What reasonable accommodations are possible for the person under Title I of the Americans with Disabilities Act 42 USC 12111, *et. seq.* or the Michigan Persons with Disabilities Civil Rights Act, MCLA 37.1101, *et. seq.*?

3. Working Out Caregiving/Living Arrangements. Other issues involve caregiving needs and arrangements:

- Can the person function independently?
- Do I need to withhold income taxes and FICA for private duty caregivers?
- Can the family caregiver take the Family Medical Leave Act, 29 USC 2601, *et. seq.*? What type of caregiving compensation arrangements can be worked out?

I. Chronic Degenerative Illness – Defined

This type of disability involves the progressive deterioration of functioning and often is associated with some neurologic disease as Alzheimer’s disease, Parkinson’s disease and Multiple Sclerosis. As our population ages, degenerative disabilities account for the fastest growing part of Medicaid expenditures and often the most expensive.

A study of the Lewin Group released from a “Public Policy Forum Alert” of the Alzheimer’s Association on March 29, 2001 gives a sense of the epidemic:

- Currently in Michigan there are 166,715 persons suffering from Alzheimer’s disease; by the year 2025 this is estimated to grow to 237,411;

- Medicaid expenditures for nursing home care for people with Alzheimer’s will nearly double from \$740 million in 2000 to \$1.342 billion in 2010.

J. Anticipating Medical Needs with Chronic Degenerative Illness

1. Managing Caregiver Stress. Unlike the trauma or catastrophic event triggering other types of chronic illness, this type of disability usually results from the gradual loss of short term memory and functioning. The insidious nature of the deterioration may cause the person and perhaps the family to live in denial of the need for more supervised care.

The emotional, physical and financial burden on the family caregivers can be intense. Unlike forms of rehabilitative illness, which have systems delivering therapies and coping strategies, frustrating gaps often exist in the systems for caregivers to deal with these diseases. Often the caregiver spouse or relative becomes vulnerable to his or her own health problems from the stress.

Developing strategies for quality of life of the person and the caregivers is a primary medical care task.

2. Reassessing the Need for Supervised Care. Anticipating the next stage of care is also a crucial task, given that there is no set treatment regimen. Families must often take the proactive step of continually assessing the condition with a local doctor or perhaps a geriatrician.

As functioning is lost, caregiving burdens increase and safety concerns arise. A change in residence and placement often become necessary. Some form of intervention usually then occurs.

Institutional care in some form – assisted living or nursing home – inevitably becomes a primary need. A 1997 survey found 42 percent of nursing home residents were diagnosed with dementia. See Center for Disease Control and Prevention / National Center for Health Statistics, *The National Nursing Home Survey: 1997 Summary*.

K. Anticipating Long-term Care Needs with Degenerative Chronic Illness

1. Waiting Lists for Admission. Unlike traumatic illnesses, this form of chronic illness rarely involves a hospitalization and easy admission to a Medicare nursing home. When Medicare is involved, patients with dementia often are “de-skilled” prior to their full benefit due to lack of ability to concentrate on the tasks.

As supervision in the home becomes more and more difficult, family caregivers must explore options with the custodial setting of assisted living and nursing homes. Screening at admission for the specialized care of dementia and any difficult behaviors increases the problems of waiting lists and denials of admission.

2. The Myth of Assisted Living. In recent years assisted living residences have become more popular and available for care. Some assisted living centers even specialize in dementia care. Two latent problems may occur, though, with the “assisted living solution”:

- Assisted living centers do not have the same obligations under federal Medicare and Medicaid regulations and the tighter state nursing home licensing regulations. When functioning, behavior or medical conditions deteriorate, the assisted living center may encourage or require discharge to another placement. The same protections and assistance on discharge may not exist here.

- Admission directly from home to an assisted living center does not trigger the “snapshot” date determination of the protected community spousal resource allowance for Medicaid.

L. Anticipating Financial Needs with Degenerative Chronic Illness

1. How Much Can We Keep? The financial issues boil down to two questions:

- Will a Medicaid spend down be necessary?
- How much can my spouse or family members keep?

Assessing asset values and titles is a key task. Often investments need to be consolidated and marshaled. The costly burden of long-term care must be compared against all income from investments and retirement. Medicaid necessity must be assessed in light of the net losses and overall family needs.

2. Don’t Miss the “Planning Window.” It is important to maximize strategies before inevitable competency issues prevent planning and necessitate court intervention.

Proper timing on transfers and title changes is important, especially when there is a need to prevent impoverishment of the community spouse or child with a disability.

M. Terminal Illness Defined

This inevitable stage has its own system of medical and long-term care. It is best defined by the standard for hospice treatment under Medicare, which requires certification by a physician as having less than six months to live. Hospice often is identified with care of the end-stage cancer patient. However, patients with the end-stage diseases as dementia and HIV also generally encounter hospice needs.

N. Anticipating Medical Needs with Terminal Illness

1. The Five Main End of Life Issues. Five main needs exist for persons dealing with end of life issues:

- Receiving adequate pain and symptom management;
- Avoiding inappropriate prolongation of dying;
- Achieving a sense of control over the end of life issues either themselves or through a proxy;
- Relieving the burden of their dying on loved ones, especially in the provision of physical care, the witnessing of their death and the decisions on life sustaining treatment;
- Strengthening relationships with loved ones, especially in the communication about the dying.

Singer, P. Martin, *et. al.*, “Quality End-of-Life Care: Patients’ Perspectives,” 281 *JAMA* 163-68 (January 13, 1999).

2. Understanding Hospice Benefits. Once linked with hospice, families encounter an array of resources centered on comfort and management of the terminal illness. Key advocacy issues involve:

- Obtaining the treating physician’s certification of having less than six months to live for Medicare payment;

- When Medicare is not available (as a younger individual), ensuring health insurance coverage;
- Understanding election of hospice terminates regular Medicare benefits;
- Knowing the beneficiary does not have to be “homebound,” and may go out;
- Understanding a “do not resuscitate” order is not required to qualify for hospice, although it may be helpful.
- Realizing hospice benefits can be extended indefinitely as long as the terminal condition persists.

O. Anticipating Long-term Care Needs with Terminal Illness

1. Payment for Placement. Many hospitals and skilled nursing facilities have hospice units, but most hospice care is provided at home. For the person residing in the nursing home, it is important for families to continue their normal payment scheme. Medicare hospice benefits do not cover the regular room and board in skilled nursing facilities.

2. Taking Care of Dependents. Assistance may be necessary to ensure the supervision or care of any persons dependent on the terminally ill person. This double jeopardy situation may involve a spouse with chronic illness or adult child with developmental disability who up to this point has lived at home.

P. Anticipating Financial Needs with Terminal Illness

1. Preventing Unnecessary Losses/Costs. The key issue on financial management involves preventing loss of assets at death. The main objectives at this stage are:

- Ensuring an orderly disposition not complicated by contentious heirs and unexpected consequences of joint ownership arrangements, beneficiary designations and inadequate documents; and
- Updating the estate plan to minimize unnecessary probate costs, income taxes, capital gains taxes and estate taxes.

2. Liquidity Concerns. When cash is short to meet the quality of life and dreams of the dying person, life insurance should be assessed for the potential receipt of benefits prior to death through loans on the cash surrender value or acceleration of the death benefit. Viatical settlements – where investment companies “buy” the death benefit – exist as a last resort. At death, liquid cash needs may become an issue to pay estate taxes when assets consist mainly of real estate or an ongoing business.

II. Planning for Anticipated and Unexpected Needs

A. Access to Quality, Affordable Health insurance

1. Access through the Health Insurance Portability and Accountability Act. Access to quality, affordable health insurance is a primary issue for persons with disabilities. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) eliminated a major obstacle to obtaining coverage after loss of group health benefits with changes in employment. Pub L No 104-191, 110 Stat 1936.

HIPAA provided the following benefits:

- People who lose *group* coverage have guaranteed access to coverage in the individual health market without regard to health status. Renewal is guaranteed.

- Pre-existing conditions cannot be excluded from coverage under group insurance policies for more than 12 months. Only pre-existing conditions occurring within the six months prior to enrollment can be excluded.

Key elements of protection are missing, though, from HIPAA:

- People without 18 months of prior group coverage do not get the protection of the Act.
- The protections for pre-existing conditions only apply when the person is seeking coverage under a group health policy
- Given that large companies typically pay 70 to 80 percent of premiums, the costs for equivalent coverage can be prohibitive.

Contrary then to popular beliefs about HIPAA, people with disabilities are vulnerable to losses in coverage. Under state law, Blue Cross Blue Shield of Michigan as a non-profit health corporation must offer health coverage to any resident of the State. MCLA §550.1101. Pre-existing conditions are screened out for six months. Some HMO's as Health Alliance Plan and Omnicare offer similar willingness to underwrite coverage even with pre-existing condition, but on a regional basis. Nevertheless, each of these private insurance routes are expensive.

2. Access through Medicare. The most common route for people with disability to gain affordable access to health care is through Medicare. For seniors, the automatic Medicare benefit at age 65 for persons entitled to Social Security retirement benefits covers the majority of the expense for most acute care medical needs. Medicare supplemental insurance makes basic coverage of deductibles and co-payments affordable.

For persons with disabilities under 65 years old the task is to obtain twenty-four months of Social Security Disability Insurance (SSDI), which then allows for Medicare benefits. Affordable Medicare supplemental insurance is available then, as well.

The real expenses occur when the disabled person under 65 is unable to qualify for SSDI or must wait out the first 24 months of SSDI eligibility. Coverage under a group health insurance plan offered through a spouse's or parent's employer is preferable at this stage. The death of the covered spouse or parent can cause a loss of those health benefits and undue expense if SSDI-type Medicare has not already been established.

B. Long-term Care Insurance – the ‘Catch 22’

1. Strict Underwriting Prevents Access. Unlike health insurance, no protections exist for access to long-term care (“LTC”) insurance for persons already suffering from a disability. Once any chronic or disabling condition occurs, companies rarely are willing to underwrite the person.

When a person is fortunate enough to have obtained coverage prior to the disabling condition, the key issues are when coverage triggers, what is covered and for what duration. Prior to state and federal legislation, policies for LTC insurance were quite inflexible about triggering benefits.

2. LTC Insurance Options Have Increased. Blanket exclusions for medical conditions except mental disorders and alcoholism have been illegal in Michigan since 1992. MCLA 500.3905. Chronic degenerative illnesses as Alzheimer's disease still, however, were indirectly screened out by the *criteria* for coverage. It was common to require standards similar to Medicare coverage for skilled care after hospital admission, which rarely occurs for the treatment of certain chronic, degenerative illnesses.

With the passage of HIPAA by Congress, providing for the tax deductibility of LTC insurance policies complying with certain requirements, options have increased considerably. Multiple

companies now offer a full cafeteria of benefits with more flexibility on triggering events. Coverage often depends on the loss of at least two activities of daily living. People can select the duration of coverage, the extent of home care and alternative living settings as assisted living and respite care. All policies in Michigan and all federal tax qualified policies must now guarantee renewal. MCLA 500.3907(1); IRC 7702B.

3. Evaluating LTC Insurance Policies. Key areas of advocacy involve:

- Evaluating the possibility of LTC insurance for the healthy spouse, parent or caregiver upon whom the disabled person depends.
- Ensuring adequate provision for home care and alternative living settings. Since 1992 Michigan has prohibited policies from requiring prior hospitalization or skilled care before covering home care. MCLA 500.3913. Home care now must be offered by policies in Michigan. MCLA 500.3907(4). Families should assess the desire and need for home care in light of health history and caregiver support.
- Comparing policies for benefit waiting periods, co-pays, maximum benefit periods and lifetime dollar limits.
- Coordinating income from the long-term care insurance benefit with public benefits as Medicare and Medicaid.

C. Other insurance

Upon disability or chronic illness, other areas of insurance which should be reviewed are:

- Short term and long-term individual and group disability insurance policies. Planning here often involves determining coverage for pre-existing conditions, proof of disability, continued coverage of the disability and ensuring coverage premium payments.
- Automobile and other liability insurance policies. These benefits must be coordinated with health insurance, workmen's compensation and government benefits to ensure payments for care related to injuries.
- Credit card, home mortgage and car loan disability insurance which may exist to protect payment of existing debt.
- Unnecessary duplications of insurance – as multiple Medi-gap policies by the elder client.

D. Benefits Planning – in General

For purposes of this outline, I presume the attorney is familiar with the rules for eligibility for LTC Medicaid. See *Fundamentals of Medicaid Planning: What Every Lawyer Should Know to Get Started*, ICLE Seminar (February 2001) In addition, knowledge of the ordinary Medicare benefits for persons over 65 years old entitled to Social Security is presumed. See David L. Schaltz and George A. Cooney, Jr., "Paying For Health Care Costs," *Advising the Older Client*, ICLE publication.

My experience indicates, though, that most practitioners are not familiar with the nuances of Supplemental Security Income (SSI) and its consequent Medicaid benefit. The same dynamic exists with Social Security Disability Insurance (SSDI) and its attendant Medicare benefit.

E. SSI-Type Medicaid Benefits

SSI is the federal income benefit which is means-tested by income and assets. It is not dependent on work history. SSI provides basic income (currently \$530 per month for individuals and \$796 for couples), but the most important benefits are the attendant Medicaid benefits. SSI does not require any work history, but is determined solely by financial need and by either age (65 or older) or disability.

SSI requires **disability** such that the person is “unable to engage in substantial gainful activity” because of “severe” impairment. 20 CFR 404.1520(b) & (c). The disability must be medically proven and be expected to last more than 12 months. The standard for children requires “severe and marked functional limitations”. 20 CFR 416.906.

- **Countable resources** may not exceed \$2,000 for a single individual or \$3,000 for a married couple, in which the spouse is not eligible for SSI. Resources include property which the person (or spouse) owns or could convert to cash for his or her *support and maintenance*.
- **Excluded resources** are items such as a home regardless of value, household goods and personal items less than \$2,000, prosthetic equipment, and an automobile up to \$4,500. For a complete list, see 42 USCA 1382b(a); 20 CFR 416.1200, *et. seq.*
- **Countable income** may not exceed the monthly SSI benefit rate. Half of a person’s earned income, plus the first \$65 per month of earned income are disregarded in determining financial eligibility. 20 CFR 416.1112. In addition, a general \$20 per month exclusion exists for all income. 20 CFR 416.112224(c)(12). After this, the benefit is reduced dollar for dollar for any income received that month.

Income includes not only cash received, but anything received by the individual in the course of a month. Income which accumulates beyond the month of receipt becomes a resource. 20 CFR §416.1207. Special rules apply to the receipt of in-kind support and maintenance. 20 CFR §416.1140-1141.

For disabled persons under age 18, the income of parents living in the household with him or her are subject to SSI “**deeming**” provisions. Under these provisions, a portion of the parents’ incomes may be deemed to be income of the person. 42 USC 1382(f)(2) and (3).

- **Divestment.** New SSI resource transfer rules enacted December 1999 limit the ability of individuals to transfer “resources” in order to establish eligibility for SSI. Penalties cause the loss of SSI (and consequently Medicaid) for the number of months equal to the amount gifted divided by the maximum SSI benefit. The penalty starts “in or after” the month in which the resources were transferred. See Section 1613 of the Social Security Act, 42 USC §1382b(e); see also Ira Salzman, “The New SSI Trust and Transfer Rules,” 9 *The Elder Law Report* 1-4 (April 2000).

Planning Tip: transfer property in the month of receipt. Direct ownership or receipt of property should be avoided by the person on SSI. However, property may be received inadvertently through inheritance, lawsuit settlement or accumulated earnings. Since the new rules only penalize transfers of “resources,” it should now be possible to transfer “income” to a third party or to a specialized trust without incurring a transfer penalty. The rule remains which allows transfer to “excluded” assets as the house, car and limited personal property. Remember “income” is any property in the month of receipt. As long as it is transferred in the month of receipt, no penalty should occur. For transfer to a specialized trust, see below.

F. SSDI-Type Medicare

SSDI is not means-tested by income or asset ceilings. Rather, it requires sufficient work history, either personally or in certain instances through a parent. SSDI provides a monthly income benefit, which may reduce or eliminate the SSI benefit. The key component, though, is the availability of Medicare health insurance after 24 months of receiving SSDI.

For SSDI benefits the Social Security Administration generally uses the same standard for determining “disability” as SSI.

SSDI provides cash benefits for individuals with disabilities who are “fully insured,” who have amassed sufficient quarters of earnings. When a parent retires, dies or becomes disabled, an individual may use the insured status of the parent to gain eligibility. The individual, though, must remain unmarried to tack on this insured status.

Advocacy Tip: seeking employment doesn’t mean loss of Medicaid/Medicare. The potential loss of health benefits deters individuals with disabilities from seeking jobs. Protections exist, however, under SSI and SSDI regulations for extended eligibility for the Medicaid and Medicare benefits despite work activity. In addition, other federal efforts exist to make employment more attainable for adults with disabilities under the Ticket to Work and Work Incentives Improvement Act. PL 106-170 (Dec. 17, 1999). Continuing disability reviews for work activity are waived when the person receives an “employment ticket.” This ticket requires participation in an employment network selected by the SSA, which assists in developing a work plan. For a detailed analysis of these protections, see Mark McWilliams, “The Ticket to Work and Work Incentives Improvement Act,” 79 *Michigan Bar Journal* 1680-83 (December 2000).

G. Estate Planning – in General

I have divided estate planning strategies by the type of disability and offer both *preventative planning tips* for anticipated needs and *responsive planning tips* for unexpected needs. I place unique emphasis on issues involving coordination of care and protection of governmental benefits.

H. Estate Planning for Developmental Disability

The “Special Needs Trust” or “Amenities Trust.” This trust has served as the primary preventative planning tool to prevent disqualification of government benefits. When unexpected assets become directly payable to a person with disability, hybrid forms of this trust may be necessary to “intercept” or shelter the assets.

The trust is designed to supplement but not replace government benefits. In addition, it provides a mechanism for management of assets for the person with a disability. The trust must be drafted and administered so that the funds will not be “available” to the beneficiary with a disability. 42 USC §1382; 20 CFR §416.1201; Miller v. Dept. of Mental Health, 432 Mich 426, 442 N.W.2d 617 (1989).

The most common form of special needs trust is a trust created and funded by a third party, as the person’s parents, prior to death.

Essential considerations are:

- Avoid language involving “**support**” and “**maintenance**.” Such language supplants SSI benefits. 20 CFR 416.1201(a); see also 20 CFR 416.120(c)(3).

- Do not mandate any distributions of income or principal to the beneficiary. Any distributions should be in the sole, uncontrolled **discretion** of the trustee. If the beneficiary cannot require distributions, it is not a countable resource. 20 CFR 416.1201(a)(1).
- Ensure strong **spendthrift protection** such that the beneficiary cannot pledge or appoint any assets, especially in lieu of any governmental benefit;
- Do not let the beneficiary create the trust. These trusts are **created by third parties**, normally the parents. The Michigan Supreme Court decided that a creditor could reach a discretionary trust for a developmentally disabled person when the beneficiary was also the settlor of the trust. In re Hertzberg Intervivos Trust, 457 Mich 430, 578 N.W. 2d 161 (1998).
- Make sure it is **irrevocable** upon the death of the grantor. Avoid language which connotes any revocable character to the trust or that it may be used for someone other than the beneficiary.
- Do not use the **beneficiary's own money**. Only with certain hybrid special needs trusts under the Omnibus Budget Reconciliation Act of 1993 (P.L. 103-66) (OBRA '93) can the beneficiary's own money be sheltered. See discussion below.
- Ensure it is funded with **enough up-front cash**. If there is any need for housing and transportation beyond the limited means provided by government programs, all of these require cash. Mortgages and financing are not an option.
- Select the **right trustee**. Every trust disbursement could potentially affect the beneficiary's eligibility for SSI and Medicaid. Given increased scrutiny by SSI, the trustee should seek expert guidance.

I. Preventative Estate Planning Strategies for Developmental Disabilities

Preventative Tip #1: tailor the trust format and avoid undue complexity.

Generally the grantor uses the format of a revocable living trust for probate avoidance purposes. Often this trust is preferred because of its flexibility for revision.

Some practitioners prefer a testamentary trust within a will, as it allows court supervision and attracts less challenges by state agencies. See Cynthia Barrett, "Elder Law Incapacity Planning," ALI-ABA Seminar, *Estate Planning in Depth*, Univ. of Wisconsin, Madison (June 1999).

Other practitioners prefer an irrevocable free standing trust as it allows additional contributions by other relatives or "unforeseen" situations where money is left to the family for the child's care. See Patricia Dudek "Trusts for Disabled Persons," ICLE 9th Annual Estate Planning Documents Seminar (January 2000).

The type of trust format will often be dictated by the anticipated circumstances. Avoid trying to accomplish too many objectives within the trust, especially given the increased scrutiny of trusts by the SSA. For example, it may be better to use an irrevocable life insurance trust for the healthy children's inheritance and save the revocable living trust for the special needs provisions.

Preventative Tip #2: do not discount the person's own legal competencies.

Evaluate the person's ability to complete at least **medical and financial durable powers of attorney**. Just because a person has a "physical impairment" that may severely affect his functioning, does not mean he does not have the mental capacity to complete these important documents. The definitions of "developmental disability" under state and federal statutes includes persons of higher intelligence. MCLA 330.1100a(19)(a); 42 USCA 6001(8).

Ensure strong gifting authority in the durable power of attorney. If the person then becomes legally incapacitated, authority exists to shelter assets inadvertently received by the person.

Preventative Tip #3: ensure written guidance exists on non-legal issues.

Include a **Letter of Instruction or Guidance** with the estate plan for the parents or family caregivers to fill out with the person. This document advises future caregivers on the best possible care for the person with a disability. Although not a “legal” document, it itemizes essential information about family history, financial management, medical treatments, allergies, habits, etc.

J. Responsive Estate Planning Strategies for Developmental Disabilities

Responsive Tip #1: intercept property in the month of receipt through an OBRA '93 Trust.

When assets are received directly in the name of the person with a disability, more specialized responses are necessary to prevent disqualification from government benefits as Medicaid. Prior to the Omnibus Reconciliation Act of 1993 (OBRA '93), the individual could not place his or her own assets in a trust without jeopardizing his or her government benefits.

Two types of trusts recognized by OBRA '93 are used in Michigan to shelter assets:

- **Exception A Trust (“Pay-Back Trust”).** Parents, grandparents, legal guardians or the court can establish this trust for a person under age 65 with a disability. Normal special needs provisions apply for distributions. At death any remaining assets are paid to the state to reimburse total medical assistance paid for the individual.
- **Exception C Trust (“Pay-To-Charity Trust”).** It is established and managed by a non-profit association. No age limitations occur here. A separate account is maintained for each beneficiary of the trust, with accounts “pooled” into one fund. At death the proceeds are retained within the overall fund for the benefit of other persons with disabilities.

A predecessor to this trust has been the **“pooled income fund”** in which a non-profit association pools funds of beneficiaries or their families to provide income to the beneficiary for life. At death the principal remains for the benefit of other similar beneficiaries. The donor receives a charitable income tax deduction. 26 USC §642(c). The Exception C Trust may differ from the tax advantageous “pooled income” fund by providing that both income and principal are used for the beneficiaries.

See 42 USC §1396p(d)(4)(A) and (c); Medicaid Program Eligibility Manual Item 405.

Responsive Tip #2: report “receipt” of trust benefits only when the trust is actually funded and distributions can be made.

New SSI anti-fraud rules provide for strict penalties, generally resulting in loss of benefits, for failure to report a “receipt” of income. See Jenny Kaufman, “SSI Steps Up Fraud Investigations and Imposes Civil Monetary Penalties,” XIII *NAELA News* 1 (February 2001). Benefits under a trust must be reported in the month of “receipt” to determine if they are countable income or exempt.

A clear definition of when “receipt” occurs does not exist in this context. The month of “receipt” should not occur until the trustee is able to create the separate trust, fund the trust and actually make a distribution of benefits. This entails at the very least the normal administrative duties of waiting the minimum four month creditor publication period under the Estates and Protected Individuals Code and obtaining any necessary federal and state estate tax clearances.

K. Estate Planning for Chronic Illness

Here I treat both types of chronic illness. While different payment systems apply primarily to each group of chronic illness – Medicare for chronic rehabilitative and Medicaid for chronic degenerative – similar estate planning strategies exist for each.

The key to successful planning is capturing the *planning window*. As competency decreases, so do the options to preserve assets, to avoid probate and to shelter for estate taxes. Ethical issues for the attorney predominate as the client's capacity wanes and long-term care expenses multiply.

The effective attorney clearly identifies “who” the client is under the circumstances. Given the illness or frailty of the client, spouses or children generally must implement strategies on the client's behalf. Quite frequently the caregiver son or daughter identifies the need for assistance and may attend the meeting with the parent(s).

Concerns about undue influence and abuse of close and confidential relationships should be flagged and handled, especially with the contentious or dysfunctional family and a caregiving relationship.

The goal is to protect the client through proper legal strategies, carefully ensuring representatives can effectively step in when necessary without undue hassle.

L. Preventative Estate Planning Strategies for Chronic Illness

Preventative Tip #1: confront lock-step determinations of incapacity.

Persons are presumed to be legally capacitated until clear and convincing evidence before the probate court to the contrary. See MCLA §700.5306 (standard for adult guardianship). Too often persons diagnosed with the initial stages of “dementia” or hospitalized for a stroke are categorically branded “incompetent” and in need of a guardian.

I have witnessed guardianship petitions filed because of wrongful intent by intermeddling heirs or simply because of inappropriate pressure by the nursing home. Once this public process has been triggered, termination of the guardianship or conservatorship process for the client can be very difficult. At times the client recovers sufficiently from a period of disorientation to proceed with private documents.

The existence of an effective medical durable power of attorney now works against the establishment of a guardianship. A new guardianship law provides that a court cannot grant a guardian powers held by a patient advocate if the court is aware of the designation and there is no allegation the patient advocate is not fulfilling his or her duty. MCLA §700.5306(2).

The interpretation of “capacity” by counsel or by the courts is often on a “sliding scale” depending largely on the *non-legal factors* as the contentiousness of the family and the client's own degree of willpower. With a contentious family I am much more willing to trigger the protections of the court. When a client shows great motivation to carry forward and the family is in agreement, I will strive hard to interpret communications in the client's favor.

Preventative Tip #2: timing is everything.

Most strategies which safely preserve assets for Medicaid or estate taxes use time against the Family Independence Agency or IRS. With an understanding of the likely next stage of the chronic illness, the counsel may enable a family to move forward on strategies as:

- Maximizing the community spousal resource allowance under Medicaid;

- Implementing “half a loaf” or serial divestment Medicaid planning strategies;
- Using life expectancy tables against Medicaid to shelter assets in the form of an exempt irrevocable annuity for the community spouse;
Note: It must be irrevocable, non-commutable (not capable of surrender) for a term certain less than the life expectancy of the person under Medicaid charts. See Medicaid Program Eligibility Manual (“PEM”) Item 405.
- Reducing the taxable estate through maximizing the \$10,000 annual gift tax exemption.

Preventative Tip #3: ensure specific authority exists in the DPA.

The following provisions in the financial durable power of attorney (“DPA”) should be carefully considered and drafted:

1. Gifting authority. The Internal Revenue Service requires express donative powers in the durable power of attorney for gifting authority to exist. Priv. Ltr. Rul. 9231003. I avoid clauses based on prior gifting history, as prior patterns rarely exist and may not be applicable. Rather, I carefully look at the family circumstances and overall intent on distributions.

If there is a child with a disability and estate taxes are not an issue, I may draft authorization for unlimited gifting authority to that particular child and authorize the gifts to be held in a trust with terms appropriate to the circumstances at that time.

To make unlimited gifts and transfers to or for the benefit of my disabled daughter, and to create an irrevocable or revocable trust agreement on my behalf for full support or special needs only, for the benefit of my disabled daughter, [insert name], with such trustee(s) as my Agent shall select, with due consideration to my then existing estate plan. My Agent is further authorized to assign, transfer, deliver and convey any or all of my assets to any revocable or irrevocable trust for the benefit of my daughter which may be then created, or which I have established prior to this date, or may establish in the future, as my Agent may determine advisable in his or her sole and absolute discretion.

If the client has a taxable estate (currently over \$675,000) and deeming of the assets into the agent’s estate will cause estate tax problems, I may restrict the gifts made by the agent to himself to an ascertainable standard. I also want to prevent any gift tax consequences related to the discharge of any legal obligation of support relating to the agent’s children.

Any gifts my Agent may make to him or herself as a permissible donee shall be limited by an ascertainable standard related to my Agent’s health, education, support and maintenance, and my Agent may not make gifts that would discharge my Agent’s legal obligation of support.

2. Authority to create and fund trusts. If it appears that the client may lose capacity before the actual estate plan can be signed and funded, specific authority to implement the plan is very helpful. At the very least, such specific authority gives the probate court judge a solid basis to implement such strategies in a protective order.

This sample clause should only be used with caution and tailored to the circumstances:

To create a revocable trust agreement on my behalf with such trustee(s) as my Agent shall select. The revocable trust shall provide that during my lifetime the trustee(s) shall distribute income or principal as I direct or as the trustee(s) shall determine for my benefit. At my death, the remaining trust assets shall be distributed to [name(s) of residuary beneficiary] or [any one or more of my spouse, my descendants, charitable organizations as my Agent, in his or her sole and absolute discretion, determines advisable]. The trust shall provide that I may amend or revoke the trust at any time. My Agent is further authorized to assign, transfer, deliver and convey any or all of my assets, including any rights to receive income or assets from any source, to the trustee(s) of any such revocable trust created by my Agent.

Preventative Tip #3: implement procedures on confidentiality and sharing of information.

Authorizations to release confidential information to agents, successor trustees and beneficiaries should be discussed and documented with the client. I often dictate a memorandum on these understandings in the presence of the client. The client then signs my notes and acknowledges the incorporation of the corresponding dictation.

M. Responsive Estate Planning Strategies for Chronic Illness

Responsive Tip #1: use court protective orders when helpful.

As discussed above, I am reluctant to commence such interventions as a guardianship unless necessary for the client's safety, medical treatment, and only then in limited forms, as a protective order.

In other instances, court intervention may be the recommended route when:

- “Authority” for a transfer is lacking in the durable power of attorney, trust or joint ownership. *See* D. Chalgian, “Medicaid Planning Through the Courts,” 1 *Elder Law Advocate* 1-2 (December 1998);
- Reformation or interpretation of an irrevocable trust is necessary;
- Establishment of an OBRA '93 payback trust for a disabled person under 65 years old who inadvertently receives property which may disqualify eligibility for government benefits; and
- Recovering wrongfully converted assets.

Example: When recovering converted assets, I have found the “Order to Show Cause” requesting the statutory double penalty usually results in a quick remedial response by the wrongdoer. MCLA 700.1205.

Note: Under EPIC, a government agency paying benefits to the client is an interested party in a petition for protective order or Conservatorship. MCLA §700.5104(2).

Responsive Tip #2: protect dependents in the ‘double jeopardy’ situation.

Medicaid law affords multiple exceptions to divestment for the protection of persons who in some form are dependent on the client. Besides the normal transfer rights to a spouse, the following exceptions exist:

- Unlimited gifts may be made directly to a child with a disability without any divestment penalty, regardless of age or marital status. PEM Item 405.
- Transfers to a trust established “solely for the benefit” of a disabled person under age 65 are not divestment. PEM Item 405. *See* OBRA '93 Trusts detailed above.
- Transfer of the “homestead” to a spouse, disabled child, child under 21, *et. al.*, as detailed below under “Dealing with the House in Light of Other Options.”

N. Estate Planning for Terminal Illness – Responsive Strategies Alone

Each of the estate planning strategies listed above for chronic illness apply to end-stage terminal illness. The key difference is the shorter planning window, which creates special considerations for the attorney. Capacity issues and the practicalities of execution of documents often predominate. In addition, documentation regarding treatment and life support is important. Last

minute strategies to reduce estate taxes may arise. Virtually all strategies at this stage are “responsive” to the exigencies.

Responsive Tip #1: understand the nuances of capacity.

As discussed above, there is no categorical determination of capacity. Rather, capacity is a continuum and often there are good days and bad days.

The attorney should understand the nuances of “capacity” necessary for the execution of different estate planning documents. While a will requires “testamentary” capacity and a durable power of attorney requires capacity for an “agency” relationship, a trust requires the higher level of “contractual” capacity. In Re: Webber’s Estate, 167 NW 937, 201 Mich 477 (1918) (less mental capacity is required to make a valid will than to enter a contract); Restatement (Second) of Agency §20 (1959) (principal must understand “agency” relationship and delegations for valid durable power of attorney).

For an excellent analysis of capacity issues, See J. Edward Spar “Attorney’s Guide to Competency and Undue Influence,” 13 *NAELA Quarterly* 7-11 (Summer 2000).

Responsive Tip #2: minimize contests.

- Carefully choose disinterested witnesses.
- Consider having a qualified medical or mental health professional evaluate the person’s awareness close to the time of signing.
- If documents are signed other than in an office setting, document your file with the reasons.
- Avoid videotaping unless it would clearly assist in defending your client’s capacity.
- Have the client sign your detailed notes as to the estate plan prior to execution.

Responsive Tip #4: ensure specific authority for medical orders.

- For home situations, inform the family of the need to execute a Do Not Resuscitate Order to avoid EMS doing CPR.
- Advise the client and the patient advocate to discuss with the doctor entry of physician’s orders, especially as to artificial nutrition and hydration.

Responsive Tip #5: maximize tax strategies.

Some specific tax strategies relevant to situations of terminal illness are:

- Convert bequests into gifts. Fully utilize the \$10,000 gift tax exemption and exclusions for direct payment of medical expenses and education. Ensure all gifts are “complete.” Treas. Reg. 25.2511-2(a) & (b). The donor should have no power to change the disposition of the gift.
- Obtain the “stepped-up” basis for capital gains tax purposes on appreciated assets. Consider transferring property of the healthy spouse to the terminally ill spouse. If the transfer takes place more than one year prior to death, or the spouse disclaims the assets at death, a full stepped-up basis will occur at death. IRC §1014(e).
- Ensure trusts are properly funded and allocated.
- Realize income taxes on accrued or deferred income in assets as annuities in which taxes may be accelerated at death and the terminally ill client is in a lower income tax bracket than the beneficiary.

- Ensure the power to disclaim assets exists for the trustee of the revocable living trust. EPIC specifically disallows disclaimer by a trust unless express authority exists within the document. MCLA 700.2902(1).

O. Coordinating Estate and Income Tax Issues

These general principles apply to estate tax planning for people with disabilities and elders:

- **Preserve the \$675,000 estate tax exemption.**

Example: Elder married couple has a joint trust with credit shelter provisions, but ineffectively separating the assets at the death of the first spouse. I generally recommend married separate trusts.

- **Convert property subject to 2 or 3 taxes to 1 tax.**

Example: Qualified plans and tax-deferred annuities have complex rules triggering both estate and income taxes. Assisting the client with an *exit strategy* can be very helpful. Contrary to common thought, naming a trust as the beneficiary of the retirement plan *may* be the recommended strategy, especially when minor or incompetent beneficiaries are involved. New rules allow more flexibility for trusts to hold qualified plan assets without accelerating the taxes. Prop. Reg. §1.401(a)(9).

- **Remove taxable growth through gifting strategies.**

Example: Set up an irrevocable free standing trust for a disabled child in which parents and other relatives can gift assets to remove them from their taxable estate.

- **Use life expectancy tables against Uncle Sam.**

Example: Client has a shorter life expectancy. She sets up a private annuity by transferring property to a family member in exchange for an unsecured promise to make specific, periodic payments for the client's lifetime according to IRS life expectancy tables. At the client's death, the property is out of her estate. *The catch:* The person must have a greater than 50% probability of surviving more than a year to use these tables. Reg. 1.7520-2(b)(3). Medical certification through a doctor's note can help justify use of the tables. If the client lives 18 months, the ability to use the tables is presumed. Id.

P. Handling the House in Light of Other Housing Options

When the client no longer resides in their house, handling the house becomes a delicate issue, particularly for Medicaid and SSI. There are important nuances dealing with title, sale and transfer issues. Many of these issues are treated within the Medicaid Program Eligibility Manual Item 405 on divestment, especially the section entitled, "Transferring Homestead to Family." See Exhibit 1 for a copy of the pertinent provisions.

The hypotheticals below illustrate the application of some of these provisions for both the elder who needs long-term care Medicaid and the disabled child who needs SSI-type Medicaid.

For purposes of discussion, Sam has Alzheimer's disease and needs Medicaid nursing home benefits. Mary is the community spouse. Ann is their only adult daughter, who is 48. Ann owns no assets and suffers from mental illness which qualifies her for SSI-type Medicaid.

- **A house titled in a trust is a "countable" asset, but this can work to the client's benefit.** Say at the time of Sam's admission to the nursing home the house was held in Sam and Mary's joint revocable living trust. Mary learns the house titled in a trust is a countable asset. PEM 401.

As such, Mary should be able to reflect this on the Medicaid Initial Assets Declaration, which maximizes the half of assets Mary can keep as the community spouse. Prior to achieving the spend down of assets for Medicaid eligibility, Mary transfers the house into their joint names as husband and wife. As there is no penalty for shifting assets from countable to exempt status, this shortens the wait for Medicaid. PEM 405. For the same reason, any mortgage on the house should not be paid down with countable assets until after the snapshot date.

- **Transfer the house to the sole name of the community spouse.** Next Mary retitles the house into her name alone to prevent Sam from receiving the proceeds in his name if she predeceases him. The transfer of the home from one spouse to another is not divestment. PEM Item 405.
- **Delicate considerations exist when the house is sold.** Mary now desires to sell the home to move with her daughter Ann to another location. The sale should not affect Sam's continued Medicaid benefit because the proceeds flow only into Mary's name and her separate assets. Prior to Medicaid eligibility, assets in Mary's name will affect Sam's eligibility because their assets are grouped together until his first month of eligibility. PEM Item 402.

If inadvertently Sam's name was still on the house after Medicaid eligibility, then the rules allow application of the proceeds from the sale of the house to a new home within 12 months without disqualification, if the proceeds are not commingled with other assets and not held in time deposits. PEM Item 400.

- **Consider disposition of the house on death.** If Mary and Ann continue to reside in the house after Sam's Medicaid eligibility, Mary should also consider transferring the house to her own revocable living trust. Within the trust she should consider disinheriting Sam. If she desires the funds to be retained for Sam at her death, she should provide for him by way of a discretionary testamentary trust. Only a discretionary testamentary trust does not affect Sam's Medicaid benefits. See PEM 401. No matter which route Mary chooses, Ann's inheritance should be protected in the form of a special needs trust.

- **Transfer the house either directly to a disabled child or for the child's sole benefit within a Payback Trust.** *Say Mary had died long ago.* Ann has continued to reside to reside at home, but needs to move now that her father is in the nursing home. Other relatives offer help. If Sam's assets are substantial, transferring all of Sam's assets, including the house, to Ann may provide for her for the rest of her life without need for SSI-type Medicaid. The transfer does not prevent Sam from qualifying from Medicaid because there is no divestment penalty for transfers to a disabled child. To enable the transfers, Sam signs a durable power of attorney appointing a relative with unlimited gifting authority. Ann does her own revocable living trust and powers of attorney appointing the relative as a trustee to assist her in the management of the assets.

If Ann needs eligibility for SSI either now or in the future, then transferring the assets to an irrevocable OBRA '93 payback trust established by the court, Sam or Ann's grandparents will shelter the assets to maintain her eligibility for SSI-type Medicaid. If the house were to be sold, then the proceeds would not disqualify Ann from SSI.

Special note for the residence of children with disabilities: Proper handling of the house can make the difference between a successful supported living arrangement for the child with a disability and insecure arrangements. A special needs trust may provide the capital necessary to purchase a home in the first place. While the home is exempt in the disabled child's name as long as it is his or her principal residence, it is generally better for the home to be held in a special needs trust. If the house needs to be sold the trustee can hold the proceeds without fear of

jeopardizing SSI benefits. To assist with home expenses, rental arrangements can be worked out with the beneficiary and one or more roommates. The trust cannot subsidize the rent of the beneficiary without affecting eligibility for SSI and Medicaid.

Example #2: Eleanore is a widow who was hospitalized for a stroke and just admitted to a skilled nursing home. She is under Medicare coverage. Mary is her agent on finances and medical decisions. The house sits vacant and just accrues expenses.

- **Rent the house.** Mary considers renting the house as a method of recovering the expenses. This will continue the exempt status of the house for Medicaid eligibility as long as she clears net income of at least six percent of the equity in the house and pays it toward nursing home expenses. She may instead opt to deduct 65 percent of the rental payment from countable income. PEM 500. There are management headaches and liability concerns which make this option less attractive.
- **Have family members make up monthly shortfalls to retain the house.** Mary may decide just to loan Eleanore a monthly amount to make up shortfalls on expenses, knowing that she ultimately will receive the house at Eleanore's death, barring estate recovery. She should avoid lump sum loans because of complicated rules to prevent deeming of the loan proceeds into countable assets. PEM 400.
- **Consider a caregiving contract.** Mary considers bringing Mom home to Mary's place. She and her husband agree for Mary to try it out and take the Family Medical Leave Act. Eleanore receives Medicare home health benefits and Mary assists her mother throughout the week. Eleanore plans on selling the house and reimburse Mary monthly for the costs of her caregiving. Eleanore and her enter into a written caregiving contract in the form of a lease, paying Mary rent and for her time assisting Mom with her care. Because a written obligation exists at the time the caregiving services are rendered, no Medicaid divestment has occurred. PEM 405.
- **Transfer the house to the caregiver child after two years of nursing care.** Eleanore has another daughter Pam who has lived in Eleanore's home for more than two years. Pam brings Eleanore home from the nursing home to attempt care herself. Eventually the care becomes too difficult and a re-admission to the nursing home is necessary. With a doctor's note that Pam provided care that otherwise would have required long-term care or waiver services, the house can be transferred into Pam's name without divestment penalty. PEM 405.

In any transaction, consider the capital gains tax issues. Before any transaction with the house, consider how this affects:

- The **two year requirement** for ownership and use of the house as the principal residence to gain the \$250,000 capital gains tax exclusion or combined \$500,000 exclusion for married couples. IRC §121. Any two years of "use" in the five years prior to sale can be selected. Last October the IRS released proposed regulations granting a special exception for out-of-residence care. The guidelines allow the exemption for just one year of "use" when the taxpayer owns the property and resides in any facility (including a nursing home) licensed by a state or political subdivision. This, too, can be any year in the five years prior to sale. Prop. Reg. §1-121-4(e).
- The **stepped-up basis** at death. This forgiveness of capital gains taxes at death does not apply to gifted property. If the donee does not plan to use the house as his or her principal residence, but rather to sell it at the donor's death, there may be significant capital gains taxes owed when the house is sold.

Finally, keep in mind Michigan and Texas are the only two remaining states not to implement an **estate recovery** program. This lien program in other states allows recovery of Medicaid payments against the house after the death of the Medicaid recipient and first after the death of any spouse, minor child or disabled child who occupies the house.

Using a revocable trust will not insulate assets from estate recovery. 42 U.S.C. 1396p(b)(4)(A). Rather, the key will be implementing strategies do not trigger divestment penalties under PEM 405 – as a transfer to a disabled child or Payback Trust. See Clifton A. Kruse, “Critical Differences in Estate Planning Strategies Between Revocable Trusts and Wills,” (Implications of the Uniform Trust Act),” *NAELA Symposium* (February 1997).

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EXHIBIT 1

Transferring Homestead to Family

It is not divestment to transfer a homestead to the client's

- Spouse
- Blind or disabled child
- Child under age 21
- Child age 21 or over who
 - lived in the homestead for at least two years immediately before the client's admission to LTC or PEM 106 waiver approval, **and**
 - provided care that would otherwise have required LTC or PEM 106 waiver services, as documented by a physician's (M.D. or D.O.) statement
- Brother or sister who
 - Is part owner of the homestead, **and**
 - Lived in the homestead for at least one year immediately before the client's admission to LTC or PEM 106 waiver approval.

Medicaid Program Eligibility Manual Item 405, at 7-8.