

# Top Ten Disability Issues To Incorporate Into Your Law Practice

## Introduction

People with disabilities continue to struggle in every part of the United States and all over the world. Recently, the United States Census Bureau issued a report (May 2006), entitled *Current Population Reports, Household Economic Studies, Americans with Disabilities: 2002, No. P70-107*, that confirms something most of us already know and experience in our law practices, “that people with disabilities, especially those with severe disabilities, live with substantially more disadvantages than people who are not disabled.” The complete report is available on the U. S. Census Bureau website, [www.census.gov](http://www.census.gov). Some key points from the report are that people with disabilities have the following:

- 1) A higher poverty rate, and the rate for people considered to have severe disabilities is more than three times that of non-disabled people;
- 2) A higher uninsured rate;
- 3) Lower education attainment;
- 4) Lower earnings;
- 5) A higher divorce rate.

Clearly, advocacy is still needed to improve the quality of life for folks with disabilities. The purpose of these materials (and this presentation) is to outline some of the more pressing issues for folks with disabilities, and provide you with resources for you to use as you start to incorporate these areas into your practices in greater numbers. It is certainly not an exhaustive list of issues or resources (although it was exhausting to put together).

Keep in mind that significant numbers of people with disabilities depend upon needs-based governmental benefits for their personal assistance services, and as a result, you as members of NAELA are uniquely suited to provide effective legal advocacy and representation to make significant improvements in the statistics cited above, in the long term care system, and most importantly in the lives of people we care about. I am so proud that people with disabilities, those of all ages, are now part of the NAELA charter! Last but not least, accommodating people with disabilities is the law; see article entitled *An ADA Lesson, No Firm is Beyond the Reach of the Americans with Disabilities Act*, by Margaret Graham Tebo, ABA Journal, August, 2006.

Before I start on the top ten list of issues, I must apologize to Catherine Sharbaugh, Esq., Surell Dean Sharbaugh, M. D., and Patricia F. Sitchler, CELA. I *really* did not mean to steal the title of this presentation from your excellent, *Top Ten Types of Disabilities Seen by Disability Attorneys* presentation at the 2004 NAELA Symposium in Hilton Head. This is an excellent resource, but my own title had much more to do with a lack of creativity and time. My love for David Letterman might have had something to do with it as well.....

So here is the countdown of my top 10:

10. Jail Diversion: How to Program Works
9. Special Education
8. Employment/Hot & New Issues
7. Taxes (Yuck!)
6. Insuring Quality Care and Avoiding Abuse and Neglect: What Research Shows
5. Decision Making by Others
4. Housing: Resources
3. Medicaid Advocacy
2. Special Needs Trust Administration
1. Olmstead/Waiting Lists: Resources

**10. Jail Diversion: How the Program Works:**

There is a general consensus that the needs of the community and society at large are better served if persons with serious mental illness, serious emotional disturbance or developmental disability who commit crimes are provided effective and humane treatment in the mental health system rather than incarcerated by the criminal justice system. It is also recognized that many people with serious mental illness have a co-occurring substance disorder. The Michigan Department of Community Mental Health requires all of its contracting local agencies to provide jail diversion. Jail diversion programs are intended for individuals alleged to have committed misdemeanors or certain, usually non-violent, felonies and who voluntarily agree to participate in the diversion program.

Effective programs support cross-system collaboration. The National GAINS Center for People with Co-Occurring Disorders in the Justice System is a center for the collection and dissemination of information about effective mental health and substance abuse services for people with co-occurring disorders who come in contact with the justice system. For more information, see [www.gainsctr.com](http://www.gainsctr.com).

People with a variety of disabilities often come to the attention of law enforcement officers as a result of circumstances related to their disability. Their arrests are frequently for nuisance offenses or minor infractions of the law. In a number of jurisdictions these individuals can be redirected at the outset, away from incarceration and into community-based mental health treatment.

Pre-booking diversion occurs before a person is arrested or formal charges have been filed. Law enforcement pre-booking diversion occurs at the time of contact with law enforcement and relies heavily on effective interactions between police and community mental health. There are several models of pre-booking programs, including special police officer response teams, police-based mental health workers and mobile crisis teams of mental health professionals.

Post-booking jail diversion programs provide access to appropriate mental health treatment outside of jail soon after arrest. Typically, these programs incorporate:

- screening of detainees for presence of mental illness;
- evaluation by qualified mental health professional of those identified through screening;
- negotiation between diversion personnel or defense attorney and the court or prosecutor to establish a mental health disposition either in lieu of prosecution or as a condition of reduction in charges or community supervision;
- linking of clients to community-based mental health services.

**A. Collaboration of Mental and Criminal Justice Organizations.**

Mental health and criminal justice entities collaborate in various ways to move defendants with mental illnesses into treatment as a condition for reduction in charges or community supervision. This collaboration involves:

- mental health programs,
- jails,
- courts,
- pre-trial services programs,
- prosecutors,
- the defense bar, and/or
- probation.

Courts are often willing to refer individuals to mental health services when a judge has confidence that the program will be effective and will ensure adequate follow-up for the person referred. In many jurisdictions, mental health programs work with various courts to refer offenders with misdemeanor and/or felony charges.

Some jurisdictions have established specialized mental health courts to handle cases when a defendant has a mental illness. Mental health courts are controversial. Some claim they are unnecessary for diversion and detrimental to the individual if they result in a criminal record or encourage use of the criminal justice system as a door into mental health treatment. The courts in various parts of the country differ greatly, even as to basic issues, such as the degree to which participation is voluntary, whether the individual must plead guilty in order to participate, whether community mental health services are expanded to accommodate the needs of those diverted by the courts, the length of time individuals are under the court's supervision, the defendants' criminal offenses and whether there are sanctions for non-compliance with treatment goals.

Evaluations of mental health courts are now underway, but to date very little data has been compiled regarding their effectiveness. A specific "mental

health court" is not essential; however, connections between the mental health and criminal justice systems have been forged at several points along the criminal justice continuum. In these communities, a comprehensive program of services and supports is offered through the mental health system and individuals are referred from various sources, including law enforcement officers, mobile mental health treatment teams, jail staff, defense attorneys, prosecutors, pretrial services, judges, and probation and parole officers. Individuals being released from jail and prison may also be eligible.

**B. Advocacy Issues and Opportunities:**

- According to the Bazelon Center ([www.bazelon.org](http://www.bazelon.org)) jail diversion has been funded for another year through the FY 2007 appropriations process. The Mentally Ill Offender Treatment and Crime Reduction Act (P.L. 108-732), championed by Senator Mike DeWine (R-OH) and Representative Ted Strickland (D-OH), would receive continued funding of \$5 million for FY 2007 in both the House and Senate Justice Department appropriations bills. This law authorizes grants to states and localities to develop programs for offenders that are collaborations between the mental health authority and a criminal or juvenile justice agency. Funds can be used for several purposes: jail diversion, improved services for incarcerated adults or juveniles and re-entry services. To be eligible, applicants must be collaborations between public mental health and a criminal (or juvenile) justice agency. The program was initiated in FY 2005, and the Department of Justice is expected to select the grantees for the first awards in the fall of 2006.
- In my experience, many of the judges are willing to allow a release to a substance abuse treatment facility. A problem arises when the person is also taking a type of controlled substance for the treatment of a mental illness: it is very difficult to get the person accepted at a substance abuse treatment facility. We then need to work with the mental health system and their jail diversion program to find a treatment location that can deal with both the illness and the substance abuse.

**9. Special Education:**

**A. Resources:**

In my early years as an attorney, working for the ARC (formerly the Association for Retarded Citizens), I spent many hours at Individualized Educational Planning Committee (IEPC) meetings, advocating on behalf of students with disabilities. This area of the law is extremely challenging, frustrating, and rewarding. As my sister is a special education administrator and my husband is a special education teacher, I no longer concentrate in this

area of practice as much as I once did (peace at the family dinner table is a beautiful thing!)-however, I must recommend the following resources to you:

- A. Frank Johns, CELA's presentation and materials entitled *Special Education: Integrating Intergenerational Estate Planning with the Needs of Children and Grandchildren with Disabilities Through Special Education and Beyond*, from the 2004 NAELA Symposium in Hilton Head.
- The National Disability Rights Network (NDRN) is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and the Client Assistance Programs (CAP) for individuals with disabilities. Collectively, the Network is the largest provider of legally based advocacy services to people with disabilities in the United States. For more information, see [www.napas.org](http://www.napas.org).
- The Arc of the United States advocates for the rights and full participation of all children and adults with intellectual and developmental disabilities. Together with our network of members and affiliated chapters, we improve systems of supports and services, connect families, inspire communities and influence public policy. For more information, see [www.thearc.org](http://www.thearc.org).

**B. Hot, New Advocacy Issues:**

**1) Getting to School Districts the Money They are Due:**

New legislation has been introduced to define how schools may bill Medicaid for health and mental health services. To address both the threat in the President's budget to Medicaid reimbursement for schools as well as longstanding issues with CMS (formerly HCFA) guidance on school billing, Senator Kennedy (D-MA) and Representatives John Dingell (D-MI), George Miller (D-CA) and Ed Whitfield (R-KY) have introduced the Protecting Children's Health in Schools Act (S. 3705, H.R. 5834). The legislation would enable schools to bill Medicaid for appropriate covered services to children with disabilities.

However, according to the United States General Accounting Office, a growing number of districts are making claims for Medicaid's reimbursement of school-based administrative services. From 1995 to 1998, Medicaid expenditures claimed for administrative activities increased fivefold in the 10 states for which we could readily obtain data. Two of these states—Michigan and Illinois—comprised the majority of the \$387 million increase in administrative expenditures from 1995 through 1998. Increases in Medicaid administrative

expenditures claimed reflect a growth in both the number of schools participating and the size of claims submitted by individual districts.

For example, from 1996 to 1997, Michigan's Medicaid administrative claims for schools increased almost threefold, from \$79 million to \$227 million, which state and school officials indicated was due primarily to an increasing number of school districts submitting claims. In contrast, Illinois school districts, which have been claiming Medicaid reimbursement since 1992, continue to identify additional activities that they believe are appropriate for Medicaid reimbursement. Thus, increases in Illinois' expenditures between 1997 and 1998—from \$89 million to \$145 million—largely reflect increased cost claims from school districts.

In addition, Arizona, Missouri, and Rhode Island provide all federal funds to the schools, whereas at least four other states allocate a portion of the federal reimbursement to their general revenue funds. Officials in two of these states said that, because state budgets fund a portion of school activities, a school district's share of federal reimbursement for administrative claims is, in principle, partially funded by the state. Under this reasoning, states believe they are entitled to some share of the federal reimbursements claimed by school districts. The three states we visited kept some portion of the federal share, ranging from 3 percent in Massachusetts to 40 percent in Michigan. Federal dollars contributed about \$1.5 million, \$8 million, and \$47 million to the fiscal year 1998 revenues of Massachusetts, Illinois, and Michigan, respectively. Since Michigan schools began claiming administrative reimbursement in fiscal year 1996, the state has retained close to \$106 million of the federal share.

Some school districts employ private firms to facilitate their efforts to claim Medicaid reimbursement. These firms typically receive as compensation a share of the revenues generated by the claims. By receiving a percentage rather than a fixed fee, these firms have an incentive to maximize the amount of reimbursements claimed. Some school districts in the states we visited paid these firms fees ranging from 3 percent to 25 percent of the federal reimbursement amount, although most commonly, the fee paid was between 9 and 12 percent. One private firm is proposing to charge a flat fee that is based on the fees it has charged historically—which were originally set as a percentage of a school district's federal reimbursement received.

Marketing materials from two private firms suggest why concerns have been expressed that school districts' administrative claims may exceed reasonable or allowable costs. In these materials, the private firms note that their objectives are to maximize Medicaid revenues for

schools and assert that they can maximize a school's claim potential by training school personnel to follow their methods for claiming costs. One firm emphasizes that, on average, its clients annually receive over 30 percent more per student than a competitor's.

Insufficient guidance, combined with uneven oversight across CMS regions, has led to questionable billing practices by states and inconsistent federal review of states' administrative claims for school-based services. CMS has not provided clear or consistent guidance to its regional offices regarding criteria for determining reasonable costs or appropriate methods for claiming administrative costs.

Without specific guidance, federal determinations of the appropriateness of administrative claiming practices are inconsistent, permitting the approval of claims that in some cases may be suspect. Some regions have conducted very prescriptive approaches to administrative cost claiming; others have been more "hands off." In those regions that have been "hands off," some states have tested the limits of reasonable and allowable standards, potentially maximizing Medicaid reimbursement inappropriately.

Close to one-half of Medicaid-eligible individuals are children, making schools an important arena for Medicaid services. Even for schools that do not directly provide Medicaid services, administrative activities can help identify, refer, screen, and enroll eligible children for appropriate, covered services. Outreach and identification activities—in many and varied settings—help ensure that the nation's most vulnerable children receive routine preventive health care or ongoing primary care and treatment. In stepping into this arena, however, some school district and state practices appear intent on maximizing their receipt of Medicaid funds through suspect financing mechanisms. Without additional guidance and consistent oversight by HCFA, many school districts with minimal knowledge of Medicaid and its billing requirements have chosen to contract with private firms. This places these firms "in the driver's seat," where they design the methods to claim administrative costs, train school personnel to apply these methods, and submit administrative claims to the state Medicaid agencies to obtain the federal reimbursement that provides the basis for their fees.

Embedded in this process are incentives for both the states and private firms to maximize Medicaid reimbursements. By being able to capture a share of the school district's federal payments, states and private firms are motivated to experiment with "creative" billing practices.

Keep in mind, that if you are advocating on behalf of a student on Medicaid, the amount of Medicaid money that the school is getting from Medicaid is information that the student is entitled to have, or it may be requested by a freedom of information request. Given the amount of negative publicity the schools got for using their Medicaid dollars to pay a private accounting firm, and for the general student populations, I found that requesting this information often made it easier to get the district to provide the disputed services for the student.

2) **Medicaid | Sen. Durbin, Rep. Davis Criticize Plan To End Medicaid Reimbursements for Special Education Services. Kaiser Reports** [Aug 31, 2006]:

Sen. Dick Durbin (D-Ill.) and Rep. Danny Davis (D-Ill.) on Tuesday warned that a plan to end Medicaid reimbursements for transportation and special education administration would affect the ability of schools to provide mandated services to low-income students with disabilities, the [Chicago Tribune](#) reports. According to Durbin and Davis, the plan, part of the fiscal year 2007 budget proposals announced earlier this year by President Bush, would reduce Medicaid reimbursements to schools nationwide by a combined \$650 million. In addition, the plan would require school districts to obtain permission from parents to receive Medicaid reimbursements each time they provide medical services to disabled students. School districts currently have to obtain permission from parents only one time. School district officials have said that "a weekly or monthly paperwork requirement would make it nearly impossible for large districts to qualify for these Medicaid dollars," the *Tribune* reports. Davis said, "It is a despicable deed that needs to be rethought and changed. If these cuts stand, we are going to leave millions of children behind." Chrisanne Gayle, Director of Federal Programs for the [National School Board Association](#), said, "It's going to have a ripple effect because more money will be directed at special ed at the expense of regular ed kids." However, Peter Ashkenaz, a spokesperson for [CMS](#), said, "We believe the financial impact on the schools will be minimal. It doesn't impact the services the children receive." (Dell'Angela, *Chicago Tribune*, 8/30/06).

3) **Individuals with Disabilities Education Act.**

Another important development is that the Department of Education has announced release of the final regulations on Part B of the Individuals with Disabilities Education Act (IDEA). These can be viewed on the Office of Special Education and Rehabilitative Services' (OSERS) website and were published in the Federal Register



on August 14, 2006. Please refer to:

<http://www.ed.gov/policy/speced/guid/idea/idea2004.html#regulations>

- a) What's the same, what's not?  
See the Office of Special Education Programs (OSEP) topic briefs prepared for the new regulations at:  
<http://www.nichcy.org/idealist.htm>

More on comparing IDEA 2004 to IDEA 1997:  
Order "The Individuals with Disabilities Education Act: Comparison of IDEA Regulations August 3, 2006 to IDEA Regulations March 12, 1999." From NASDSE, is the National Association of State Directors of Special Education. This \$15 book compares the old and the new regulations section by section. <http://www.nasdse.org/documents/SbSorderform.pdf>

One-stop IDEA shopping! The U.S. Department of Education has launched its dedicated Web site to provide a "one-stop shop" for resources related to IDEA 2004 and its implementing regulations: the statute, regs, video clips on important topics, links to the toolkit, a Q&A on IDEA, and more <http://idea.ed.gov>

And last but not least...

**b) Community-based meetings on IDEA.**

This fall OSERS (the Office of Special Education and Rehabilitative Services) will be hosting a series of community-based public meetings on IDEA in three cities. Each participant will receive a copy of the new regulations on CD, as well as a copy of the Tool Kit on Teaching and Assessing Students with Disabilities (also on CD). Other materials will be available in print form, including copies of the three model forms required under the reauthorization: Individualized Education Program (IEP), Notice of Procedural Safeguards, and Prior Written Notice.

For these free public meetings, registration will take place on site. Each meeting will begin with an internal reception with Assistant Secretary Hager and Director Posny, followed by a presentation about the regulations, including a taped welcome from Education Secretary Margaret Spellings, information about the regulations and the dedicated IDEA Web site, and an opportunity to ask questions about the regulations and OSERS' implementation plans. The dates and locations are:

Dallas, TX  
Thursday, Nov. 2, 2006

Denver, CO  
Wednesday, Nov. 8, 2006

Sacramento, CA  
Tuesday, Nov. 14, 2006

For more details, visit:  
<http://www.ed.gov/policy/speced/guid/idea/idea2004-schedule.html>

**c) Fees:**

In June, 2006 the Supreme Court of the United States ([www.supremecourtus.gov](http://www.supremecourtus.gov)) ruled 6-3 in *Arlington Central School Dist. Bd. of Ed. v. Murphy* that the Individuals with Disabilities Education Act (IDEA) does not authorize the recovery of expert fees by prevailing parents in an IDEA action. The Court ruled that the legislative history to the contrary was not enough to overcome the lack of an explicit statement in IDEA legislation that expert fees are recoverable.

“When Congress says in the IDEA that children are entitled to a free and appropriate public education, it means just what it says – *free*,” said National Disability Rights Network Executive Director, Curt Decker. “An education is not free if parents who win cannot recover the expenses paid in challenging unlawful school district decisions. To this end, we call on Congress to enact legislation allowing for the recovery of expert fees, so that the promise of the IDEA is met.” A copy of the *amicus* brief can be found at [http://www.ndrn.org/amicus/briefs/0603edu\\_Murphy.pdf](http://www.ndrn.org/amicus/briefs/0603edu_Murphy.pdf)

The Supreme Court decision can be found at <http://www.supremecourtus.gov/opinions/05slipopinion.html>

**4) Public Schools Paying for Private Schools:**

For a critical look at public schools paying for private schooling for kids with disabilities, see New York Times Editorial Observer: ***How Schools Pay a (Very High) Price for Failing to Teach Reading Properly*** by Brent Staples, June 19, 2006 at <http://www.nytimes.com/2006.06/19/opinion>.

8. **Employment/Hot & New Issues:**

A. **The final Disability Service Improvement (DSI) regulations, 71 Fed. Reg. 16424 (March. 31, 1006) became effective nationwide on August 1, 2006.**

B. **PASS:**

Under a plan to achieve self-support (PASS), a person with a disability on SSI may be able to set aside part of their income and/or resources to meet an employment related goal. The income or resources set aside, which can include their SSI benefits, will not be counted in determining the amount of the person's SSI payment or impact their eligibility. The final rule is available on the Federal Register website: [www.gpoaccess.gov/fr](http://www.gpoaccess.gov/fr). This final rule, which was published on May 16, 2006, implement changes in the law that became effective January 1, 1995!!!!!!

C. **DRA TANF:**

New regulations have been issued to implement changes made by the DRA to the Temporary Assistance for Needy Families (TANF) program. On June 29, 2006 the Department of Health and Human Services (HHS) released interim final regulations on TANF and invited public comment.

The DRA made several changes that could prove disastrous for TANF beneficiaries, particularly people with mental or physical disabilities. Most problematic were increases in the work-participation rates required of states and requirements for the development of a standardized set of restrictive work activities. State flexibility has been critical to helping individuals with mental illnesses to transition successfully into employment. Rules that rob the states of the ability to receive credit for activities that assist these individuals in meeting their work-hour requirements or to provide services (such as rehabilitation) or education opportunities that lead to employment could significantly harm recipients with mental illnesses. These individuals are now at risk of being sanctioned for failing to comply with the new, tighter rules on work.

The DRA required HHS to issue regulations on select areas of current law. Defining what activities can count towards the work-participation rates is among those. Unfortunately, HHS generally opted to narrow the definition of these federally listed work areas and included limits on the extent to which important activities designed to address barriers to employment (such as mental health and substance abuse treatment) can count toward the state's work-participation rate.

For more detailed information, see an analysis provided by the Center on Budget and Policy Priorities (CBPP) and the Center for Law and Social Policy

(CLASP) at <http://www.cbpp.org/7-21-06tanf.htm> The regulations are effective now, and states must begin to make necessary changes in order to comply with them.

**D. Self-Determination and the Development of Microenterprises:**

**Microenterprises** are very small businesses. According to Paulette J. Williams, Associate Professor of Law at the University of Tennessee College of Law in Knoxville, the development of microenterprises “can be seen as part of a broader reliance on private market initiatives and business development as a way for low income people to become self sufficient, and as a movement away from reliance on government funded benefit programs.” For more information, see Ms. Williams’ article attached as Attachment 1, “*Making a Difference: A Role for Lawyers in Economic Development*” from the Journal of Affordable Housing”, Volume 15, Number 1, Fall 2005, review of *The Legal Guide to Microenterprise Development* by Susan R. Jones, published by the ABA.

For more information regarding individualized employment for people with disabilities through self determination, and individualized Medicaid budgets see: [www.self-determination.com](http://www.self-determination.com)

**E. Aids and the Workplace:**

“Medical Advances in the 25-year battle against AIDS make lawsuits over workplace bias more difficult,” asserts attorney Steve Seidenberg, in the August 2006, ABA Journal, in his article entitled, “*The HIV Conundrum*”.

**F. Microsoft Computer Grants**

John M. Williams reviewed Microsoft’s new vista accessibility program in Exceptional Parent Magazine’s August 2006 issue- see [www.eparent.com](http://www.eparent.com). The program apparently provides personalized recommendations for accessibility tools and settings in the operating system that are likely to improve the special needs person’s ability to see, hear and use their computer. Hopefully that will allow more folks to maintain their connections to their community and their jobs. A Google search (I know, but I could not help it!) resulted in a number of articles about how Vista is an example of corporate leadership and a commitment to accessibility. For years, I have complained about Bill Gates and my dependence on his “products”, especially when new operating systems kept coming out every year, but.... between Vista, his work on poverty, use of an incentive trust, and his support for Bono (U2 Rocks!) I just may have to admit, I was wrong.....

## 7. **Taxes (Yuck!):**

### A. **Property Taxes.**

On May 4, 2006, the Michigan Supreme Court ruled on the property tax exemption requirements for charitable institutions. Many non-profit community housing organizations joined forces to write an amicus brief in support of the housing organization qualifying as a charity and one that provided a public health purpose. However they left, “further examination of the meaning of public health purpose” for another day. Further litigation on these issues is expected for the housing organizations on these issues.

### B. **Income Taxes:**

The Working Families Tax Relief Act of 2004 (WFTRA), effective in 2005, redefined the definition of “dependent” as it applies to health and welfare benefits and defined contribution pension plans. According to Dennis T. Blair and Brian J. Malynn in their article from the Benefits Law Journal (Vol. 19, No.1, Spring 2006) entitled “*Solving the Dependent Definition Dilemma in Employee Benefit Plans*”, WFTRA also unintentionally created technical glitches. The outcomes could be exclusion of individuals that employers thought were covered, and possible taxable income for employees when covering certain individuals. The article includes a description of the individuals that qualify for tax favored treatments as well as model plan document language employers can use to describe the dependents their plans cover. So-do we care about this?

#### 1) **Advocacy:**

Let’s take an example from a typical day in a law practice:

Susie is 23 years old and has a disability. She still lives at home with her parents and attends school (Michigan has special education services from the ages of 0-26). If she is a dependent under IRC Section 152, then she can continue to be covered by her father’s employer provided health insurance, and the benefit was not included in her dad’s gross income. WFTRA changed the definition and may cause her to lose this coverage, and/or have it become included in her dad’s gross income. Before WFTRA a child could have been a dependent regardless of age or gross income.

#### 2) **Resources:**

Two other great resources on taxes are: 1) the materials and presentation of Robert M. Morgan, Ruth A. Phelps, and David Lee Rice entitled, *Guiding Your Client To Get The Best Tax Break in*

*Caregiving*, from the NEALA Symposium, 2006 in Washington, D.C.;  
2) Thomas J. Murphy's report on the session in the July 2006  
ElderLaw Report (see [www.elderlawanswers.com](http://www.elderlawanswers.com)).

### C. Gift Taxes:

**Advocacy Note:** Do not forget that clients can give more than the yearly gift tax exclusion amount for the direct payment of medical expenses.

- **Section 2503.-Taxable Gifts**

*26 CFR 25.2503-1: General definition of "taxable gifts" and of "total amount of gifts." (Also Section 2512; 25.2512-8.)*

**Medical expenses paid on behalf of another.** The direct payment of unreimbursable **medical** expenses to the service provider by a donor on behalf of another is not subject to **gift** tax under section 2503(e) of the Code, effective for gifts made after December 31, 1981. Rev. Ruls. 54-343 and 73-612 amplified.

**Rev. Rul. 82-98**

- **Section 213.-Medical, Dental, Etc., Expenses**

*26 CFR 1.213-1: Medical, dental, etc., expenses.*

**Medical expenses; handicapped condition; capital expenditures.**

Listed are expenditures eligible for the medical expense deduction if made for the primary purpose of accommodating a personal residence to the handicapped condition of the taxpayer, the taxpayer's spouse, or dependents who reside there.

**Rev. Rul. 87-106**

- **Section 213.-Medical, Dental, etc., Expenses**

*26 CFR 1.213-1: Medical, dental, etc., expenses*

The cost of maintaining a mentally retarded son in a specially selected home, to aid in his adjustment from institutional living to community living, qualifies as a medical expense; Revenue Ruling 58-481 superseded.

**Rev. Rul. 69-499**

### 6. **Insuring Quality Care and Avoiding Abuse and Neglect: What Research Show:**

The July 11, 2006 issue of Forbes Magazine reported that the United States may not be able to meet future demand for personal assistance workers to look after the elderly at home and keep them out of institutions. On July 21, 2006, the Chicago Sun Times reported an update on their investigation from 2005 that found 100 registered sex offenders and 61 parolees convicted of non-sex crimes were living alongside persons with illnesses, disabilities, and of age. The investigation helped prompt a law that made Illinois the first state to require criminal background checks on folks living in nursing homes and became effective in July 2006. Michigan just started background checks on folks working in licensed settings (but not those using

Medicaid or public dollars in a less restrictive setting). It is making it harder to find folks to work as personal assistants, a provider agency director told me... To compound the issue consider the following articles:

- A. *No Longer Immune, Court Opens Door to Cases Claiming Link Between Autism and Vaccine Preservative*, by Wendy N. Davis, see Attachment 2, July 2006, ABA Journal.
- B. *Injury Prevalence Among Children and Adolescents with Mental Retardation*, Slayter, Garnick, Kubisiak, Bishop, Gilden, and Hakim, June 2006, Journal on Mental Retardation, from the American Association on Mental Retardation, Volume 44, Number B3. This article addresses the issue that childhood injuries lead to increased morbidity and result in significant costs to public insurance programs. People with mental retardation are overwhelmingly covered by Medicaid. They are also at a very high risk for injury. The data about the injuries was collected via CMS and found that almost 40% of children and adolescents with mental retardation are experiencing injuries that may lead to reduced potential for community inclusion. This report will be used for targeting new and ongoing prevention initiatives as well as assisting in the evaluation of the initiatives' effectiveness.
- C. *Assessing Risk of Injury of People with Mental Retardation Living in an Intermediate Care Facility*, Edward A. Konarski and Marc Tasse, September 2005, Journal on Mental Retardation, from the American Association on Mental Retardation, Volume 110, Number 5. This article reports a study that determined that the percentage of people who experienced an injury significantly increased across the levels of increased risk on the author's test. It is hopeful that this assessment will become a reliable and valid method for predicting injury risk level. In English, that means that it might be possible to identify folks who are prone to injury (like me), so that supports might be put in place to prevent the harm.
- D. *Sexuality and Mental Retardation: Unmet Challenges*, Sundram and Stavis, August 1994, Journal on Mental Retardation, from the American Association on Mental Retardation, Volume 32, No. 4. Although this article is a bit older, it is great! It examines the challenges in support of people with mental retardation in the community, the nature and extent of the problem of sexual abuse, and the differing judicial approaches taken to assessing their ability to consent to sexual relations.

So, what does this all depressing stuff mean for quality care? Do we as people accept our responsibility to care for those among us that are unable to care for their self without some help? Please review Terry W. Hammond's Essay about his investigation into living conditions for people with disabilities in Texas. It is a compelling story about a state that is unwilling to protect its

own. Terry is interested in hearing from NAELA members to determine if Texas is unique or a reflection of our nation. ....(Attachment 3).

**E. Further resources:**

**1) Shriners:**

I tend to think otherwise- consider the following positive(s):

I have always known that the father of one of my oldest and dearest friends is a “big wig” with the Shriners. I really did not know what that meant, except that he volunteered a great deal, got us tickets to the circus, and maybe worked to save treasures of ancient days (ok- I admit it I love Nicholas Gage, and the movie National Treasure). In the past year, we invited her husband to ice skate with my husband against the Red Wing Alumni in a fund-raiser for United Cerebral Palsy Association of Detroit (I just came off the board of directors after nine years)- and her parents attended the game to cheer our men on (thank goodness Steve Yzerman was still a Red Wing)- . Anyway, her dad explained to me that the Shriners have a hospital network of 22 hospitals across North America, and provide all the services at no cost to the kids with disabilities or their parent(s) FOR FREE!, who knew? I mean, I have known this family forever, and worked in this field for what seems like forever, how did I not know this??? That is the wonderful thing about this work, just when you think you can not take one more piece of bad news, you learn about something so generous..... it renews your faith!! For more information see the article about their Integrated Care Model in the August 2006, Exceptional Parent Magazine, or go to [www.shrinershospitals.org](http://www.shrinershospitals.org).

**2) Dental Care Efforts:**

In 2004, The Commission on Dental Accreditation adopted new standards for dental and dental hygiene education programs to ensure the preparation of practitioners to provide oral health services for persons with special health care needs. Implementation of this revised standard was required by January 1, 2006. This change was a result of a 3-year effort to bring about the needed change in response to disappearing resources for dental care for folks who are medically underserved. The next step will be to advocate for loan forgiveness for those who provided these necessary services. See: *Mandating Education of Dental Graduates to Provide Care to Individuals with Intellectual and Developmental Disabilities*, American Association on Intellectual and Developmental Disabilities AAIDD (formerly known as AAMR, Mental Retardation), Volume 44, No. 3, June, 2006.



## 5. Decision Making by Others:

### A. **Terri Schiavo: A Disability Battle:**

The years of conflict around Terri Schiavo's situation was a tragedy for her whole family. Yet they have educated us about ourselves and forced us to ponder very controversial issues regarding end of life treatment, the value and quality of life, the right to make our own medical decisions and the preservation of self-determination, and the ability to ensure our wishes are followed regarding end-of-life treatment when we can no longer speak for ourselves.

Terri Schiavo suffered a cardiac arrest, which resulted in brain damage from insufficient oxygen to the brain in 1990. At that time, Terri had not executed any document such as a living will that expressed her preferences regarding life-sustaining treatment. A feeding and hydration tube was inserted as a result of the severe brain damage due to her inability to swallow or eat or drink. Her husband, Michael Schiavo, was appointed guardian later that year. Terri then received extensive treatment and rehabilitation through 1994.

In 1998, her husband finally petitioned the court to authorize the removal of Terri's feeding and hydration tube, asserting that Terri would have wanted it that way. A guardian ad litem was appointed to review the case and represent Terri's interests, and concluded that Terri was in a "persistent vegetative state" with no chance of improvement.<sup>1</sup> The judge also concluded that there was clear and convincing evidence that Terri would have wanted the tube removed upon the review of statements she made to her husband and other evidence. Terri's parents and siblings disputed the fact that she wanted the tube removed, as well as Terri's condition being described as a "persistent vegetative state," and whether there were available medical treatments to improve Terri's condition.

From that point, there was an explosion of litigation between Terri's husband and her parents surrounding whether the feeding and hydration tube should be removed. The matter also led to extensive involvement by Jeb Bush, the Florida legislature, the U.S. Congress and President Bush. Numerous moral and legal arguments were raised regarding involvement of government institutions and courts in an extremely personal matter, how religious values affect our society, and the preservation of life. Nevertheless, at minimum, the Schiavo case provides a good example and reminder for all of us why it is important that we plan for incapacity, no matter how young we are, or our health status, through identifying *who* we want to make medical decisions on our behalf, and what our preferences are regarding medical decisions and life-sustaining treatment.

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<sup>1</sup> To view the guardian ad litem report by Richard L. Pearse, Esq. in full, see <http://www.miami.edu/ethics2/schiavo/122998%20Schiavo%20Richard%20Pearse%20GAL%20report.pdf>

**B. Federal Law Regarding Self-Determination and End of Life Decision-Making.**

The first case to address end-of-life decision-making by the state's highest court was *In re Quinlan*, 70 NJ 10, 355 A.2d 647 (1976), where the New Jersey Supreme Court held that the right to make medical treatment decisions, including right to refuse or withdraw medical treatment, is a constitutional right to privacy. The U.S. Supreme Court later confirmed this in *Cruzan v. Missouri Department of Health*, 497 US 261 (1990), and affirmed that there is a constitutionally protected right to withhold or withdraw life support, and that food and hydration was considered "medical treatment." As a result of *Cruzan*, the Federal Patient Self-Determination Act was passed, providing legal recognition of our constitutional right to self-determination and medical decision-making, including the use of advanced directives whereby an individual may state their wishes regarding medical treatment to ensure they are followed should they become incapacitated.

**C. A State Study: Medical and Life-Sustaining Treatment Decisions in Michigan.**

**1) When there is No Power of Attorney for Health Care:**

If there is no "advanced directive," Michigan law will allow another person to make medical decisions on behalf of an individual, also called "substituted decision-making." The relevant case is *In re Martin*, 450 Mich 204 (1995), with facts remarkably similar to the Schiavo case. The court held that a surrogate decision-maker may order life-sustaining treatment withheld or withdrawn only when it is clear that particular person would have refused treatment under those *exact* circumstances or circumstances highly similarly to current situation involved. Otherwise, the State's interest in preserving life prohibits withdrawal of life-sustaining treatment if there is no clear and convincing evidence of the individual's preferences. In *In re Martin*, the court determined that the statement made by the individual in response to a television program that he would not want to live like a vegetable was **NOT** clear and convincing evidence to support the removal of a feeding tube after an accident that left him completely paralyzed, unable to talk, eat or drink. Thus, there is a fairly high standard of proof required before someone can decide to withdraw life-sustaining treatment on another individual's behalf. That makes it particularly important that individuals take the proper steps to minimize the chances that a scenario such as Terri's and Mr. Martin's will happen to them.

**2) The Capacity to make a Power of Attorney for Health Care:**

In 1990, the Michigan legislature authorized the Durable Power of Attorney for Health Care. MCL 700.5506. The statute states, "[a]

person 18 years of age or older who is of sound mind at the time a designation is made may designate in writing a person who is 18 years of age or older to exercise powers concerning care, custody, and medical treatment decisions for the person who made the designation.... [A] person who is named in a designation...shall be known as a patient advocate and a person who makes a designation shall be known as a patient." Id.

It is important to note that the patient must be of "sound mind." Id. This is the same standard as seen in the realm of last wills and testaments. In order to execute a will, "[a]verage mental capacity at the time of the execution of the will is not necessary to its validity. A less degree of mind or capacity is requisite to execute a will than to make a contract covering the same subject matter." Bean v Bean, 144 Mich 599, 108 N.W. 369 (1906); see also, Rivard v Rivard, 109 Mich 98, 66 N.W. 681 (1896). The Michigan Supreme Court, in determining whether a person was of sound mind, has stated "[t]he weak have the same right as the prudent and strong minded to dispose of their property." In re Getchell's Estate, 295 Mich 681, 295 NW 360 (1940). Presumably this principle holds true for decisions concerning a person's health as well.

**3) Michigan's Patient Advocate: Compare this to Your States Medical Surrogacy Rules:**

The patient advocate's powers spring into place when the patient, "is unable to participate in medical treatment decisions." MCL 700.496(8). The statute allows for the filing of a petition in probate court to resolve disputes that may arise over whether the person is able to participate in medical treatment decisions. Id. Practitioners must realize that there is a difference between the ability to give informed consent and the ability to participate in treatment decisions. Further, the ability to participate, however cursory (e.g., ask simple questions), could bar an agent's involvement in the medical decision-making process.

It should be added that a person eighteen years or older, who is of sound mind, or their Agent under a Durable Power of Attorney for Health Care can execute a Do Not Resuscitate Order. (The statutory form is required and it must be signed by the person's attending physician and two witnesses, at least one of which is not a spouse, child, grandchild, sibling or presumptive heir). Michigan licensing requirements may still require direct care staff to contact medical services if a resident suffers a cardiac arrest. However, when the emergency medical personnel arrive, they may follow the Do Not Resuscitate Order. In particular, the Patient Advocate must take "reasonable steps to follow the desires, instructions, or guidelines given by the patient while the patient was able to participate in care, custody, or medical treatment decisions, whether given orally or as

written in the designation.” *Id.* Furthermore, the law states that if the *Patient Advocate Designation* and the authorization of Patient Advocate to make decisions regarding life-sustaining treatment is “clear and convincing,” then the Patient Advocate may make such decisions for that individual. *Id.* This may be set forth in the actual document, or, in more detail, in a supplemental document such as the *Health Care Values History Form*. See Attachment 4.

The Patient Advocate form should be made available to all health care providers involved with your medical treatment, family members, and friends. The Patient Advocate Designation form can be found at various websites, as well as health care providers. However, it is beneficial for an attorney to assist with the drafting of the Patient Advocate Designation to ensure not only that the document meets the legal requirements, but that it clearly expresses the individual’s wishes.<sup>2</sup>

Additional Resources:

- For a *Durable Power of Attorney for Health Care/Patient Advocate Designation* form from the State Bar of Michigan, see [http://www.michbar.org/elderlaw/pdfs/dpoa\\_hc.pdf](http://www.michbar.org/elderlaw/pdfs/dpoa_hc.pdf)
- For a brochure on *Planning for Medical Decision-Making* from the National Academy of Elder Law Attorneys, see <http://www.naela.org/Applications/News-app/Files/MedicalDecisionMaking.pdf>
- For the form *Clear and Convincing Evidence of Your Wishes*: <http://www.agingwithdignity.org/5wishes.html>
- National Right to Life website: <http://nrlc.org>
- For information regarding *Docubank* – an electronic storage and access service for advanced directives: <http://www.docubank.com>
- For a comprehensive timeline and summary of events of the Schiavo case, see: <http://www.miami.edu/ethics2/schiavo/timeline.htm>
- See *Washington Watch*, Vol 3 Issue 3, for a good summary of the history and perspectives of the disability community: [http://www.aamr.org/ww/WW\\_%20Vol3\\_Issue%202.pdf](http://www.aamr.org/ww/WW_%20Vol3_Issue%202.pdf)

**D. Patient Advocate Designation for Mental Health Treatment: A Provision other States should look at:**

There have been recent developments in the law that will have a significant impact on persons receiving mental health treatment as well as planning for

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<sup>2</sup> The author acknowledges the scope of this article does not address end-of-life decision-making for people who are not considered competent in the eyes of the law to express their wishes (i.e., minors, or persons born with significant challenges).

those who may experience a need for mental health treatment. As you may have heard, Michigan's legislature recently passed Kevin's Law, whereby probate courts are now authorized to order assisted outpatient treatment. In response to the more intrusive and restrictive nature of Kevin's Law and to protect the ability of individuals with mental illness to plan for their own incapacity, additional legislation was passed in response to Kevin's Law to allow for a designation of an agent to make mental health treatment decisions on the principal's behalf.

**1) Kevin's Law:**

Kevin's Law allows the probate courts to order "assisted outpatient treatment" (herein referred to as "AOT") for a person with mental illness *without* having to demonstrate that the individual posed a danger to himself or others, which is the standard that was used by courts to order inpatient psychiatric hospitalization for persons with mental illness. Thus, this legislation, added to the Michigan Mental Health Code, gives judges the ability to order involuntary *outpatient* treatment under specific circumstances. It is important to note that this did not change MCL 330.1208, which defines individuals with "serious mental illness" as one of the three groups of individuals for which priority shall be given by the Community Mental Health Services Program.

Kevin's Law was introduced in response to the brutal beating of Kevin Heisinger, a University of Michigan student, by a man with mental illness in 2000 in the men's room of the Kalamazoo Amtrak and bus station. The man with mental illness had been diagnosed with schizophrenia and a history of medication non-compliance.

**2) "Person requiring treatment":**

According to the new legislation, AOT can be ordered by a court if the following requirements are met:

- a. Person has a mental illness;
- b. Is unable to understand the need for treatment due to impairments, and is unlikely to participate in treatment voluntarily;
- c. Intervention is necessary to avoid a relapse or harmful deterioration of his/her condition;
- d. Is currently noncompliant with treatment recommended by a mental health professional; **and**,
- e. The noncompliance with treatment has resulted in
  - (1) Placement in a psychiatric hospital, prison, or jail at least 2 times within the last 48 months, *or*

- (2) The individual's committing one or more acts, attempts, or threats of serious violent behavior within the last 48 months.

See MCL 330.1401(1)(d).

**3) Procedures for Petition for AOT:**

Any individual over the age of 18 may file a petition with the court for an Order for AOT if the individual meets the above requirements. The petition must include:

- a. Facts supporting the need for AOT;
- b. Names and addresses of any witnesses to the facts; and,
- c. Names and addresses of any individuals/entities currently providing mental health treatment to the individual; and
- d. Names and addresses of the nearest relative, or guardian, if known, or if none, a friend of the individual, if known.

See MCL 330.1433(1).

The rights of the alleged "person requiring treatment" regarding a petition for AOT remains the same as those for a hearing for involuntary hospitalization under the Michigan Mental Health Code, including the following:

- Court must give notice of the petition and time and place of hearing to the individual or his or her representative, the petitioner, the spouse or guardian, or other relatives. MCL 330.1453.
- Within 4 days of receiving necessary documents, the court must give the individual a copy of the petition and each clinical certificate, and notice of rights to a full court hearing, to be present at hearing, to be represented by legal counsel, to demand jury trial, and to have independent clinical evaluation. Counsel for the individual must be allowed to have sufficient time for investigation and prep, and must be permitted to present evidence. MCL 330.1454; 330.1455; 330.1458 to 1464.

**4) Orders for AOT:**

If the court finds at the hearing that the individual meets the criteria of a person requiring AOT, and that outpatient mental health treatment is **not** scheduled to begin for the individual that includes case management services or assertive community treatment team services, the court must order the person to receive AOT through his/her local Community Mental Health Service Program (CMHSP). In addition, the order for AOT may include the following services:

- Medication

- Blood or urinalysis tests to determine compliance with prescribed medications
- Individual/group therapy
- Day or partial day programs
- Educational and vocational training
- Supervised living
- Assertive community team treatment services
- Alcohol and/or substance abuse treatment
- Alcohol and/or substance abuse testing for an individual with a history of alcohol/substance abuse and testing is necessary to prevent a deterioration of his/her condition (which is subject to review every six months).
- Any other services prescribed to treat the individual's mental illness and either assist the individual in living and functioning in the community or prevent a relapse or deterioration that would reasonably likely lead to suicide or the need for hospitalization.

MCL 330.1433(3). See also MCL 330.1100a(6).

**5) Duration of the AOT Order:**

The new provisions also limit the duration of Orders for AOT to 180 days, or 6 months. MCL 330.1472a(1)(d). If the CMHSP or mental health professional overseeing the AOT believes that the individual is still a "person requiring treatment," and that the individual is not likely to continue treatment voluntarily, a petition may be filed with the court at least 14 days before the expiration of the order for a second order for AOT. MCL 330.1473. If the court grants a second order for AOT, it cannot continue past one (1) year. MCL 330.1472a(2)(b).

If AOT is needed beyond the second order, a petition may be filed again under the same procedures for continuation of the second order, but it is not effective beyond one year. MCL 330.1472a(3)(b). Petitions may be filed prior to the end of each one year period until the individual no longer requires treatment. MCL 330.1472a(4).

**6) Noncompliance with Order for AOT:**

The CMHSP or mental health provider must immediately notify court upon a determination that the person requiring treatment is not complying with the Order for AOT. The court then may require one or more of the following *without* a hearing:

- The individual must be taken to the preadmission screening unit established by the CMHSP for hospitalization;

- The individual must be hospitalized for a period of not more than 10 days; and/or
- Upon recommendation by the CMHSP, the individual is to be hospitalized for a period more than 10 days but no longer than the duration of the order for AOT or not longer than 90 days, whichever less.

**7) Preferences regarding Mental Health Treatment:**

Fortunately, there are also provisions that attempt to minimize the use of this more intrusive intervention by the court regarding outpatient mental health treatment. In the new statutes, the court *must* consider any preferences and medication experiences reported by the individual or designated representative, whether or not an individual plan of service exists, and any directions included in a durable power of attorney or advanced directive. See MCL 330.1433(5).

If individual does not have a durable power of attorney or advanced directive in place, prior to expiration of the AOT Order, the CMHSP must determine whether the individual wishes to establish a durable power of attorney or advanced directive. If the individual wishes to, the CMHSP is required to direct the individual to the appropriate resources for assistance in developing an advanced directive. *Id.*

In addition, if AOT Order conflicts with previously existing advanced directives, durable powers of attorney, or individual plans of service, the AOT Order must be reviewed for adjustment by an independent psychiatrist not involved with developing AOT Order, and the court shall state its findings on the record, or in writing if the court takes matter under advisement, including the reason for conflict. See MCL 330.1433(6).

**E. Patient Advocate Designation for Mental Health Treatment:**

Previously, the statutes regarding a Patient Advocate Designation (“PAD”) only permitted Patient Advocates to have authority to make decisions regarding medical care and end of life treatment. The new provisions have been passed and include the ability to designate a Patient Advocate for *mental health* treatment decisions when the individual is unable to do so, and requires the Patient Advocate to follow the individual’s preferences regarding mental health care. See generally, MCL 700.5506 to 5512; 700.5515; 700.5520.

The rationale for the passage of such legislation for a PAD for mental health treatment, pushed by various advocacy groups, is to minimize the intrusive nature and court involvement of ordering AOT. In order to minimize the AOT provisions, not only is a PAD for mental health treatment now available, but as mentioned above, courts *must* consider the preferences of the individual regarding treatment if specified in a Patient Advocate Designation or any other writing, when considering court orders for AOT. In addition, the mental



health provider must determine whether an individual participating in AOT wishes to execute a PAD for mental health treatment.

**1) Triggering Event for the Patient Advocate to make Mental Health Treatment:**

The Patient Advocate may act on an individual's behalf to assist with mental health treatment decision-making when a physician **and** a mental health professional, determines the individual is unable to participate in mental health treatment decisions. In addition, the individual may designate specific physicians and/or mental health professionals to make this determination. MCL 700.5515(2).

**2) Specific Grants of Authority for Mental Health Decisions:**

The law requires, however, that the Patient Advocate will *only* have the ability to assist with psychiatric hospitalizations of the individual and forced administration of medications if it is *clearly stated* by the individual in this Designation. MCL 700.5509(h). In addition, the Michigan Mental Health Code requires that the Patient Advocate may also consent to electroconvulsive therapy (ECT) only if given explicit authority to do so. MCL 330.1717.

**3) Waiver of the Right to Revoke for Mental Health Decision-Making:**

Typically, all individuals who execute PADs have the ability to revoke, or cancel, their PADs. However, the Michigan legislators were aware and attempted to accommodate individuals who feel that any decisions they may make while they are unable to make their own mental health treatment decisions, will not necessarily be in their best interests. Thus, the new statutes provide the ability for the individual to waive their right to revoke their PAD, regarding only mental health treatment decisions. MCL 700.5515(1).

There are safeguards in place so that the waiver of revocation does not continue on indefinitely. If it is communicated at a later time that the individual wishes to revoke their PAD for mental health treatment while it has been determined that the individual is unable to participate in decisions regarding their own mental health treatment, and the individual is receiving mental health treatment at that time, that mental health treatment shall not continue for more than thirty (30) days. MCL 700.5515(1). After that time, one of the following may occur:

- No further treatment will be necessary;
- Assistant outpatient treatment is ordered by a court of competent jurisdiction; or,
- Involuntary psychiatric hospitalization is ordered by a court of competent jurisdiction under Michigan Mental Health Code.

**4) Binding Effect on Mental Health Professionals:**

Under the new law, mental health and health care professionals must follow the individual's wishes regarding mental health care. However, there are exceptions to this rule. The treating professionals are not bound to follow that desire if one or more of the following apply:

- In the opinion of the mental health professional, compliance is not consistent with generally accepted community practice standards of treatment;
- The treatment requested is not reasonably available;
- Compliance is not consistent with applicable law;
- Compliance is not consistent with court ordered treatment; or,
- In the opinion of the mental health professional, there is a psychiatric emergency endangering the life of the patient or another individual and compliance is not appropriate under the circumstances.

See MCL 700.5511(4).

These exceptions are unlike the provisions related to health care decisions, where the health care professional *must* honor the preferences expressed by the individual in a PAD or other writing under all circumstances. Thus, these exceptions have raised some serious concerns by advocates due to the ease by which an individual's preferences may be ignored. Moreover, these exceptions have even raised questions regarding the legality of this provision under the Americans with Disabilities Act due to the differences in treatment of preferences regarding medical and mental health treatment, as a similar challenges have been raised in another state whereby a similar statute was struck down by a federal court. See *Hargrave v. Vermont*, 340 F.3d 27 (2<sup>nd</sup> Cir. 2003). Whether the current Michigan statute will withstand scrutiny under the Americans with Disabilities Act remains to be seen.

**5) Acceptance of Patient Advocate Designations:**

Lastly, the recent legislation revised the required statements that must be included in the *Acceptance of Patient Advocate* to be signed by the nominated Patient Advocate or Successor Patient Advocates upon the execution of the PAD. Previously, when the PAD only included decisions regarding medical care, the *Acceptance* forms required nine (9) limiting statements. Now, the *Acceptance* must include ten (10) limiting statements, one of which reflects the grant of powers to the Patient Advocate for mental health decisions. See MCL 700.5507.

Furthermore, it is argued that the new statutes require the re-drafting and re-execution of the *Acceptance of the Patient Advocate* for

previous *Patient Advocate Designations* even for only medical treatment decisions executed prior to these legislative changes.

The additional language added to the statutes relating to PADs clearly raise drafting challenges due to the different standards between medical and mental health treatment decisions. See Attachment 5 for sample draft of a *Patient Advocate Designation for Mental Health Treatment*. See Attachment 6 for a sample draft of a *Patient Advocate Designation for Medical & Mental Health Treatment*.

Clearly, there are benefits and concerns raised by these new changes both in regards to Kevin's law and the PADs for mental health treatment. The practical effect of these new legislative changes, however, is unknown at this time. Nevertheless, it will be important for individuals, advocates and family members to stay apprised of these issues, so that the individual's rights and preferences regarding mental health treatment are honored should they become incapacitated and unable to make their own mental health decisions.

#### **F. Incapacity of Business Owners:**

Another somewhat common situation is when families request assistance for dealing with the possible incapacity of a loved one who owns a family business. This is of particular concern if the business employs a large number of employees, and when there is no one who clearly possesses the power to oversee the operations of the business while a possible petition for guardianship or conservatorship is pending. Often times, business owners have engaged in estate planning, and a dispute could be arising to determine a trigger or springing power to allow a Successor Trustee to take over management of the trust and the business interests if they are held in the trust.

In such circumstances, a *Petition for an Order to Seal Records* (see Attachment 7) may be suitable in order to prevent irreparable injury, loss or damage to the business interests of the company should it be discovered by other individuals, such as employees, or third parties conducting business that the individual's capacity is in question. This is particularly important to avoid abuse or exploitation of the individual's business interests. MCR 8.119(F) states in pertinent part:

*(1)...a court may not enter an order that seals court records, in whole or in part, in any action or proceeding, unless*

*(a) a party has filed a written motion that identifies the specific interest to be protected,*

*(b) the court has made a finding of good cause, in writing or on the record, which specifies the grounds for the order, and*

*(c) there is no less restrictive means to adequately and effectively protect the specific interest asserted.*

For a sample *Petition for an Order to Seal Records*, see **Attachment 7**.

### **Additional Reference Materials:**

- *Strictly Business; Planning Strategies for Privately Owned Business; by Cahoone, Gibbs and Riley, 2002.*
- *Business Succession Planning & Beyond Multidisciplinary Approach to Representing the Family-Owned Business by Dreux and Goodman, 1997, ABA, Section of Real Property, Probate & Trust Law.*
- *Mock Trial: Appointment of a Guardian Against the Alleged Incapacitated Person's Wishes, Presentation and Materials from the NAELA Symposium, April, 2006.*
- *Guardianship and Less Restrictive Alternatives, AARP Foundation National Legal Training Project at: [www.aarp.org/nltp](http://www.aarp.org/nltp).*

#### **4. Housing: Resources:**

The disability community believes that all people should have the right to live in the community with the supports they need, and advocates for public policy support this right. Adults with developmental disabilities should have the opportunity to pursue the same range of lifestyles and opportunities as other members of the community.

##### **A. HOUSING FIRST**

A team of NPR News radio and Web journalists is producing Housing First, a yearlong special reporting project Housing First explores why it's so difficult for Americans with special needs to find good housing -- and how the lack of housing often stymies their efforts to join, and flourish in, the mainstream of society. <http://www.npr.org/news/specials/housingfirst/index.html>

##### **B. Other Resources:**

- Technical Assistance Collaborative at: [www.tacinc.org/](http://www.tacinc.org/)
- NEW: *Opening Doors*, Issue 28 - The Section 8 Project-Based Voucher Program. A new HUD Final Rule published on October 13, 2005 now makes it much easier for Public Housing Authorities (PHAs) to use the Project-Based Voucher program. This issue of *Opening Doors* provides a basic overview of these new HUD voucher policies, including how the disability community and PHAs can work together to expand affordable, accessible, and permanent supportive housing opportunities.
- Community Housing Network: a network, a community economical development organization dedicated to building and management of resources for the benefit of people with disabilities. Their link

includes information on their Housing Resource Center and their Housing Manual at: [www.communityhousingnetwork.org](http://www.communityhousingnetwork.org)

- *Home Control Through Trust and Estate Planning* by Theresa M. Varnet and Richard C. Spain, January 2004. A 60 page booklet on understanding government benefits, preserving eligibility for government benefits through estate planning, and planning for residential options for persons with developmental disabilities, "HOME CONTROL" was originally commissioned by and funded through a grant from the Illinois and Missouri Planning Councils on Developmental Disabilities. A copy of "Home Control Through Estate and Financial Planning" costs \$15.00; contact:

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Chicago, IL 60602  
(312) 220-9112

- *A Bill of Rights for Homeowners in Associations: Basic Principles of Consumer Protection and Sample Model Statute* by David A. Kahne, July, 2006, AARP, Public Policy Institute at [www.aarp.org/ppi](http://www.aarp.org/ppi)
- *Meaning of Homeownership for Individuals With Developmental Disabilities: A Qualitative Study*, Volume 44, Number 4-295-303: In-person interviews were conducted with 7 homeowners selected by 6 state home-ownership programs as representing good examples of home ownership by individuals with developmental disabilities. Recurring themes were found in the choice of a home, advantages and disadvantages of home ownership advice. Although the process of purchasing the home was described as lengthy and difficult and ownership brought unexpected problems, these were outweighed by the financial, social, and psychological benefits of owning one's own home. Written by David Hagner, Judith Snow, and Jay Klein, see Attachment 8.

### **3. Medicaid Advocacy:**

According to the Report entitled: *Moving Beyond the Tug of War: Improving Medicaid Fiscal Integrity*, by Schwartz, Gehshan, Weil, and Lam, dated August 2006, and funded by the Robert Wood Johnson Foundation, Medicaid's administration is "complex due to its size and scope, and it is made more complex by its joint federal/state oversight and administration." The report states that, "The key features of a program with fiscal integrity are a clear set of rules, established through a public process, administered fairly and openly for all to see...Fundamentally, improving Medicaid's fiscal integrity is at least as much of a political challenge as it is a substantive challenge." NAELA and its members, through legal advocacy collectively and individually must be a part of addressing this challenge!

**A. Legal Challenges:**

Legal challenges are becoming more common, not only on financial eligibility but on disability, and the amount duration and scope of services (See Wolff v. Ohio Department of Job and Family Services, [www.sconet.state.oh.us](http://www.sconet.state.oh.us); Ohio Court of Appeals, Tenth Appellate District, January 19, 2006). NAELA must be prepared for the challenges. Consider this disturbing comment contained in the Preliminary Report on Medicaid Reform from the National Governors Association, June 15, 2006; “Federal reforms are needed to constrain the broad ability of judicial decrees in Medicaid cases that clearly impede state innovation and reform. In a time of shrinking resources and growing demand it is not realistic to ask states to manage these complex programs with court decrees overriding sound management decisions.” The report calls for Judicial Reforms to allow for the right of states to locally manage the program. So how do we fight back??

**B. Fighting Back:**

- 1) Read and re-read the excellent materials and listen to the tape from the April 2006, NAELA Symposium entitled: Walter Mitty Goes to Court: Section 1983 for Non-Litigators (and Working with a Litigation Team) by Reixach, Vasiliadis, and Landsman. I am proud that the Westside Mothers case came from Michigan- it is an important case: read it (Westside Mothers v. Haveman, 289 F 3rd 852 (2002)).
- 2) Keep in mind that as H. David Blair states in the ElderLaw Answers article entitled “A chat with the Country Lawyer” who matched Wits with Scalia and Co. Over Medicaid and Won, dated 6/26/2006, ‘...we’ve got a whole lot of people on Medicaid that are not elderly!’”
- 3) Preadmission Screening and Resident Review (PASRR) requires the state’s mental health authority to review the appropriateness of nursing facility care for each resident of a Medicaid facility. 42 USC 1396r(e)(7)(B)(I). If the applicant is determined to require nursing facility services, they may be admitted. If they are determined to also require specialized services, the state must provide or arrange for the provisions of services while the person resides in the facility, and the applicant can appeal any unfavorable determination. 42 CFR 431.200, 483.210(a)(1). This can be a powerful legal/advocacy tool when assisting folks with securing services to transition out of a nursing home.

**2. Special Needs Trust Administration:**

**A. DRA and Special Needs Trust:**

- 1) DRA 2005 adds a new section to the Medicaid Act that greatly expands the states’ options to impose cost sharing on Medicaid beneficiaries. It

establishes separate cost sharing options for prescription drugs and non-emergency use of the emergency room. Furthermore, the states can now permit Medicaid-participating health care providers to condition the provision of care, items or services upon the payment of the cost sharing amount. Trustees will need to be careful when using trust funds to pay a co-payment or cost sharing amount.

For example, In the Case of Schott v. Olszewski, (2005, WL 588751 6<sup>th</sup> Cir. Michigan, Attachment 9), where the Court held:

- a) In circumstances in which Medicaid recipients are initially denied Medicaid coverage, they must be reimbursed for out of pocket payments made for services provided during the retroactive coverage period.
  - b) That medical expenses can be reimbursed, even if they are paid by a third-party on behalf of the beneficiary.
  - c) That medical expenses shall be reimbursed at the rate actually paid not the Medicaid rate.
- 2) The DRA also includes a new state option to establish a non-emergency medical transportation brokerage program. The purpose is to move to a more cost-effective way to provide medical care to beneficiaries as Medical Assistance. This will allow the state to get matching dollars for this service. This is important as transportation is a service that trustees are often requested to pay for the beneficiary of a special needs trust, and the trustee must be able to assure they are coordinating any payments from the trust with this covered service (if the state chooses this option). Furthermore, the trustee may need to pursue a fair hearing or a 1983 action on the denial of these services.
  - 3) Self-Determination, Cash and Counseling, Money follows the person, are all programs that are supported by DRA and Trustees will need to know how to use them in coordination of trustee disbursements. For more information see: [www.cashandcounseling.org](http://www.cashandcounseling.org).
  - 4) For more information on the above changes and other advocacy issues from DRA, see the No. 224, Spring 2006 Newsletter of the National Health Law Program, entitled the Health Advocate.

## **B. Bankruptcy:**

Bankruptcy and consumer protection issues continue to be a problem for people with disabilities and Trustees of Special Needs Trusts and their counsel need to be aware of the issue and be able to either address them or refer and coordinate same

with other members of the bar. Mental Health agencies and other creditors tend to be aggressive in their collection efforts, and this is an area where counsel can immediately reduce stress on the client. I refer you to the presentation and materials from the NAEELA Symposium, April 2006, *entitled Consumer Frauds Targeting Older Consumers – Research, Education and Litigation* by Sally Balch Hurme, Esq., Prof. Rebecca C. Morgan, Esq. and Stephanie Whittier, MSW. These materials are great and include a step by step process on how to opt-out of pre-approved credit offers, which many Trustees of Special Needs Trusts should be able to assist the beneficiary with.

**C. IRAs:**

PLR 200620025 recently released by the IRS held that a D 4 A trust is a conduit trust for income tax purposes (rather than an accumulation trust), and therefore the life expectancy of the person with a disability could be used to determine the required minimum distributions from the IRA to the trust. This will allow for great planning options for folks who become disabled later in life or for whom families did not plan well.

**D. Dual Eligibles:**

Large numbers of people with disabilities are enrolled as beneficiaries of both Medicaid and Medicare. Trust administration issues for these folks will include coordination of both programs along with private resources or insurance. More recently, coordination of Medicare Part D Coverage, and Medicare Appeals for denial of services are hot issues. I refer you to The Center for Medicare Advocacy, Inc. for the most up to date information Medicare at: [www.medicareadvocacy.org](http://www.medicareadvocacy.org)

**1. Olmstead/Waiting Lists: Resources:**

Solving the waiting list issue is the greatest challenge facing people with special needs and their families. It will impact how and when and where they receive their Medicaid or mental health services. See the following resources on this complex issue:

- A. *Crisis in the Community: Waiting Lists for MR/DD Services*, by Shelia Stasko, September 2005, Exceptional Parent Magazine;
- B. *Who will Care for Disabled Kids? Advocates push for them to live independently when aging parents aren't able to take care of them anymore*, by Kim Kozlowski, May 17, 2006, Detroit News.
- C. *Average Per Person Medicaid Long-Term Services costs Increased at One Fourth the Rate of Inflation between 1993 and 2004 with Shift to Home and Community-Based Services*, by Lakin, Braddock, and Smith, Volume 43, Number 5 of Mental Retardation, October 2005, American Association on Intellectual and Developmental Disabilities AAIDD (formerly known as AAMR).



- D. Status Report: *Litigation Concerning Home and Community Services for Persons with Disabilities* by Gary A. Smith, Attachment 10. **IF YOU READ ONE THING BESIDES YOUR MATERIALS IT SHOULD BE THIS.**
- E. *Supporting Aging Caregivers and Adults with Developmental Disabilities in Future Planning*, by Heller and Caldwell, Volume 44, Number 3, of *Mental Retardation*, June 2006, American Association on Intellectual and Developmental Disabilities AAIDD (formerly known as AAMR). This article reports on a peer intervention for aging caregivers. The intervention significantly contributed to families completing a letter of intent, taking action on residential planning, and developing a special needs trust. The article confirms what we should all know, “Caregiving burden significantly decreased for families in the intervention and daily choice-making of individuals with disabilities increased.” We should all work with family advocacy groups and former clients, to connect our clients to their peers.
- F. Olmstead. See Attachment 11 for more on Olmstead and Attachment 12 for sample complaints and information.
- G. Policy Resource Brief, this Policy Research Brief reviews available research on the costs and outcomes of community service provisions for people with intellectual disabilities (or “mental retardation”) and development disabilities, with a particular emphasis on residential services. It focuses on a number of key issues related not only to public expenditures, but also to funding systems, related policies and regulations, and their impact on service systems, on specific service types, and on service users. It was prepared by Roger J. Stancliffe and Charlie Lakin of the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, Minneapolis. Charlie Lakin may be reached at 612/624-5005 or [lakin001@umn.edu](mailto:lakin001@umn.edu), and Roger Stancliffe at [rogers@localnet.com.au](mailto:rogers@localnet.com.au). See Attachment 13.

Finally, keep in mind that discrimination in admissions to facilities based on disability (or functioning level) violates the Rehabilitation Act of 1973 and the ADA, see Wagner v. Fair Acres Geriatric Center, 49 F.3<sup>rd</sup> 1002 (3<sup>rd</sup> Cir. 1995).