

# 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 NAELA 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).



## FROM THE READING ROOM

### Making a Difference: A Role for Lawyers in Economic Development

Paulette J. Williams

*The Legal Guide to Microenterprise Development*  
Susan R. Jones  
American Bar Association (2004); \$24.95  
Paperback; 110 pages  
available from [www.ababooks.org](http://www.ababooks.org)

New York Lawyers for the Public Interest (NYLPI), a nonprofit law office that operates a pro bono clearinghouse to provide free legal assistance for eligible low income individuals and community groups, brokered the relationship between a microenterprise development program and a law firm. Over several years more than 15 attorneys from Debevoise and Plimpton worked with the New York Association for New Americans (NYANA) Microenterprise Development Program which helps immigrant and refugee entrepreneurs learn about the American marketplace and how to apply for a loan to start a business. The law firm has drafted lending documents for NYANA, America's largest not for profit provider of educational, social, legal and business services to refugees and immigrants. The firm's assistance to microbusinesses has included workshops on legal compliance and technical assistance to individual entrepreneurs as well as assisting with a landlord and tenant dispute and representing a microentrepreneur in the purchase of a fast food business.<sup>1</sup>

This is one of many examples from Susan Jones's book *Legal Guide to Microenterprise Development* describing the work that lawyers do in representing microenterprise organizations. Increasingly, entrepreneurship and economic development, not direct government assistance, are being seen as providing the pathway out of poverty. Jones has identified microenterprise development as an area of need where lawyers can play a big role in promoting economic development and makes the case that microenterprise development is an effective mechanism for both job creation and self-employment. She presents the complex issues in the field that require legal expertise and provides a resource guide that addresses the many obstacles lawyers face in doing this work.

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Although the goal of eliminating extreme poverty in the world is far from achieved, microenterprise development has been shown to be a powerful tool in global efforts to alleviate poverty.<sup>2</sup> Yet, it is a tool that has been very much underutilized, both domestically and internationally. Susan Jones's book is an invaluable resource that details the role that lawyers can play in promoting microenterprise development in the United States.

She specifically sets out to

(1) provide legal guidance to attorneys who are not familiar with the microenterprise field and who want to represent microenterprises; (2) assist microenterprise practitioners with understanding the types of legal issues that may arise in their programs and the legal issues that microbusinesses may encounter; (3) provide legal guidance to attorneys who want to represent the small businesses assisted by microenterprise programs; and (4) identify legal resources that support microenterprise programs and microbusinesses.<sup>3</sup>

Microenterprises are very small businesses. Microenterprise organizations are agencies, usually nonprofit, that support microenterprises by extending loans and providing business training and other technical assistance to entrepreneurs. In the first chapter, Jones explains microenterprise development as part of an economic development strategy aimed at alleviating poverty. Historically, microenterprise development was an important economic development tool in developing countries of Africa, Asia, and Latin America that began in the 1970s.<sup>4</sup> In the United States, a variety of affordable housing, job programs, and other types of targeted community development programs have emerged since the 1980s with the aim of creating jobs and alleviating poverty. In fact, microenterprise development 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.

Lending and technical assistance are major activities of microenterprise organizations. Some make small direct loans while others develop relationships with community lending institutions. Loans range between \$500 and \$35,000, and the technical assistance takes the form of business training, credit development and repair, financial planning, and developing access to new markets.

Jones emphasizes the importance of microenterprise development because it has a great impact "that facilitates poverty reduction and encourages economic self-sufficiency, human dignity, and community empowerment."<sup>5</sup> She points to studies showing that microenterprise development organizations make a significant contribution to the alleviation of poverty.<sup>6</sup>

This introductory chapter also contains definitions of key words and phrases used in the field of microenterprise development<sup>7</sup> and explains the "design elements" used by the various programs, including "entrepreneurial training and technical assistance, access to capital, access to new markets and asset development, and financial planning."<sup>8</sup> Within her dis-

discussion of entrepreneurial training and technical assistance, Jones describes small business development centers (SBDCs), which play a key role in providing assistance "such as accounting, business planning, and related start-up or expansion matters"<sup>9</sup> to small businesses.

### The Role of Lawyers

Lawyers who represent microenterprise organizations have responsibilities that are similar in many ways to those of legal counsel to lenders and other business developers. They create loan documents and counsel clients on entity formation. In her chapter on the lawyer's role, Jones lists a wide range of functions that go beyond those of the typical business lawyer, such as serving on boards of organizations in the community or writing articles on entrepreneurship.<sup>10</sup> She makes a convincing case that these added responsibilities are worth the effort in terms of the benefits derived from the work.

In representing microenterprise organizations, the lawyer's goals are broader than just creating a new business or helping the client make a profitable loan. These programs try to develop human capital in the form of job skills, self esteem, and progress toward self sufficiency, none of which can be easily measured on a balance sheet.

By representing individual microbusinesses, lawyers apply their skills in familiar ways. Typical services include structuring business entities; registering trademarks or service marks; obtaining licenses, permits, and variances; handling tax matters; buying, selling, or valuing the business; handling real estate closings or leases; and drafting and reviewing loan documents and other contracts. Jones provides very helpful checklists of business and legal issues that are useful in any type of business practice.<sup>11</sup> In one of her final chapters, Jones summarizes the "Legal and Business Issues for Microbusinesses"<sup>12</sup> and includes thumbnail descriptions of intellectual property considerations, such as copyright, trademark, patents, licenses, and trade secrets.

### Special Considerations for Microenterprise Programs

The heart of Jones's book and its major contribution is the guidance that it provides for lawyers who represent microenterprise programs, those organizations that fund and provide technical assistance to microbusinesses. In organizing a microenterprise program, the lawyer needs to consider the law of nonprofit corporations, taxation, insurance, banking, and bankruptcy, among other issues. The chapter on legal formation issues<sup>13</sup> as well as an extensive appendix of microenterprise resources<sup>14</sup> gives lawyers a head start.

Generally speaking, microenterprise programs are organized as tax-exempt nonprofit corporations. The first step is to incorporate under the nonprofit corporation laws of the state in which the organization operates. With goals of fostering economic development and alleviating poverty, these organizations can qualify for federal tax exemption under Section

501(c)(3) of the Internal Revenue Code. One factor for programs to consider is whether to form a new entity or to operate under the auspices of an existing nonprofit corporation. The decision to form a separate entity is a complex one and requires careful analysis of the relationship between the organizations that are planning to work together.

Even though microenterprise organizations are engaged in business development, they fit within the definition of an entity "organized and operated exclusively for . . . charitable . . . or educational purposes"<sup>15</sup> by virtue of the fact that they involve "relief of the poor and distressed or of the underprivileged, advancement of education, and promotion of social welfare through organizations formed to lessen neighborhood tensions, eliminate prejudice and discrimination, or combat community deterioration or juvenile delinquency."<sup>16</sup>

Other formation issues include obtaining a state tax exemption, making sure appropriate insurance coverage is in place, and ensuring a thorough understanding of lending laws. As lending institutions, microenterprise programs are governed by a complex array of consumer protection laws, including the Truth in Lending Act,<sup>17</sup> the Equal Credit Opportunity Act,<sup>18</sup> the Fair Credit Billing Act,<sup>19</sup> the Fair Debt Collection Practices Act,<sup>20</sup> the Fair Credit Reporting Act,<sup>21</sup> not to mention state and local usury laws.

Lawyers representing microenterprise organizations engaged in lending funds to small businesses will create loan documents and institute debt collection procedures and bankruptcy practices for use by their clients. Microenterprise organizations as well as other "institutions that lend money, such as credit unions, banks, and groups that provide hands-on technical assistance and training to microbusinesses also face risk of being sued. In all instances, the best way to protect against these types of claims may be to obtain insurance."<sup>22</sup> Jones recommends and discusses directors' and officers' coverage and workers' compensation as well as general liability insurance.

### Targeting Specific Populations

In her chapter on planning issues for microenterprise programs,<sup>23</sup> Jones advises that groups do an assessment of the needs of particular groups in their areas to determine which populations are most in need of services. A thorough needs assessment also will help new programs to avoid duplication of efforts. Depending on the target group that the organization chooses to address, a wide range of legal issues may arise. Some examples of the specialized microenterprise groups that Jones describes include peer lending groups, welfare to work groups, immigrants and refugees, domestic violence survivors, ex-offenders, and others.

Peer lending groups, also known as circle lending or group lending, involve groups that guarantee each other's loans and provide peer support to ensure that payments are made. Jones provides an example of a single mother on welfare who borrowed \$800 from the Women's Self-Employment Project in Chicago to support her sales of lotions, cologne, and perfumes.

She and the other members of the borrowing circle used the funds to purchase inventory and used peer pressure from other members of the group to make sure that loans were paid in a timely fashion.<sup>24</sup>

Jones's discussion of microenterprise development organizations that target welfare recipients is an excellent example of the strategies employed to address the issue of welfare reform. In 1996, Congress enacted the Personal Responsibility and Work Opportunity Reconciliation Act<sup>25</sup> (PRWORA), which replaced Aid to Families with Dependent Children, an income support program that provided cash benefits to needy families with children. Major distinctions between PRWORA and earlier welfare laws were that states could not use federal funds "to assist a family for more than five years . . ." and that PRWORA "requires adults to be 'engaged in work' within two years of receiving assistance . . ."<sup>26</sup>

Jones describes a major research study supported by the Charles Stewart Mott Foundation and other research organizations "to determine under what circumstances self employment could be a route to economic self sufficiency for recipients of Temporary Assistance for Needy Families (TANF)."<sup>27</sup> She strongly encourages states to include microenterprise development as a significant part of their welfare strategies. Lawyers need to be involved in structuring these programs at the state level. Although TANF dollars can be used to support microenterprise development, the programs need to be carefully designed to comply with the statute and avoid the imposition of penalties.

Jones lists twenty-two recommendations identified by microenterprise advocates and researchers to assist states in maximizing microenterprise development, including ways to utilize state dollars so that they do not count against federal time limits. Another strategy is to define initial microenterprise development as vocational training.<sup>28</sup> She illustrates the benefits of this approach with an example of a welfare recipient with a third-grade reading level who had difficulty applying for jobs or for food stamps because she could not fill out the necessary forms. A microenterprise program taught her how to start her own housecleaning business; she attended literacy classes, has been off welfare for six years, and makes \$48,000 a year operating her business.

Other populations that can benefit from microenterprise development present legal issues that are specific to those populations. For example, some business development programs target immigrants and refugees who are starting their own businesses or creating self employment. Immigration lawyers should be consulted in these cases. Whether it is legal for immigrants to work at all, or to perform certain types of work, will depend on their classification as asylum applicants, lawful permanent residents (green card holders), nonimmigrant students or visitors, temporary workers, or trainees. Navigating the intricacies of the Immigration Law can have a real impact on the rights of clients to remain in the United States.

Collaboration between microenterprise organizations and advocates for domestic violence survivors presents an important opportunity to rebuild

lives. "After exiting an abusive relationship and while healing from the abuse, microenterprise training and its support systems can foster economic independence for the woman and her children."<sup>29</sup> Domestic violence attorneys need to be aware of this available resource for their clients.

Microenterprise programs have reached out to people with physical and mental disabilities. Jones cites an article on the Abilities Fund,<sup>30</sup> a national organization that represents a partnership between the microenterprise industry and the disabled community.

Jones sets out the legal issues that need to be addressed when microenterprise organizations work with ex-offenders; the homeless; arts, crafts, and entertainment businesses; faith-based programs; youth; rural communities; and Native American communities. Each of these populations can benefit from targeted microbusiness development activity, but each requires a degree of specialized legal knowledge, and Jones points out clearly the important role that lawyers can play in this area.

### Funding

In a short chapter on identifying funding sources for microenterprise programs,<sup>31</sup> Jones points out that funding these programs is a major challenge. The growing Socially Responsible Investment movement, which identifies businesses where ethical values are a factor in the investment decision, offers opportunities to support microenterprise programs. Jones urges legal organizations to make loans and long term investments in programs to support microentrepreneurs.

Increasingly financing is available from revolving loan funds, Community Development Financial Institutions, or seed money from foundations. As the legal community becomes more involved with microenterprise development, lawyers can help the business world understand the financing problems as well as the legal issues associated with this type of development.

### Conclusion

Susan Jones has brought to light the important area of microenterprise development, making a strong case for its enormous potential for helping to alleviate poverty. She presents information with abundant examples of how lawyers working in a variety of fields—business, banking, domestic violence, disabilities, civil rights, immigration, and welfare—have contributions to make. Microbusiness is not the solution to the problem of poverty but, for many, it is a way to create jobs or self employment. For microbusinesses to work, the support of microenterprise organizations is needed. For microenterprise organizations to succeed, lawyers must lend their knowledge and expertise to the effort. The extensive list of resources that Susan Jones provides is an excellent place to start.

1. SUSAN R. JONES, THE LEGAL GUIDE TO MICROENTERPRISE DEVELOPMENT 53-54 (2004).

2. Lea Uhrinova, *Doing Business with Microfinance*, 33 CORP. EXAMINER 5, 7 (2005) (arguing that commercial banks should be more involved with micro-finance development.)
3. JONES, *supra* note 1, at 12.
4. Of several examples of microenterprise development from the developing world, "[o]ne of the most successful and renowned . . . is the Grameen Bank in Bangladesh," which is described in DAVID BORNSTEIN, *THE PRICE OF A DREAM: THE STORY OF THE GRAMEEN BANK AND THE IDEA THAT IS HELPING THE POOR TO CHANGE THEIR LIVES* (1999). JONES, *supra* note 1, at 1.
5. JONES, *supra* note 1, at 3.
6. *Id.* at 3, 4.
7. *Id.* at 5-7.
8. *Id.* at 8.
9. *Id.* at 8 n.20.
10. *Id.* at 16 (listing "25 Things Lawyers Can Do for Microenterprise Programs").
11. *Id.* at 21-24.
12. *Id.* at 79-87.
13. *Id.* at 25-38.
14. *Id.* at 91-115.
15. I.R.C. § 501(c)(3).
16. JONES, *supra* note 1, at 28-29 (citing Treas. Reg. § 1.501(c)(3)-1(d)(2) (1997)).
17. 15 U.S.C. §§ 1601-1608 (as amended 2000).
18. 15 U.S.C. §§ 1691-1691(f) (as amended 2000).
19. 15 U.S.C. §§ 1666-1666j.
20. 15 U.S.C. §§ 1692-1692o (as amended 2000).
21. 15 U.S.C. §§ 1681-1681v (as amended 2000).
22. JONES, *supra* note 1, at 32-33.
23. *Id.* at 39-73.
24. *Id.* at 41-42.
25. Pub. L. No. 104-193, 110 Stat. 2105 (1996), codified at 42 U.S.C. §§ 601 *et seq.* (2000).
26. JONES, *supra* note 1, at 44.
27. *Id.* at 1 (citing MICROENTERPRISE AS A WELFARE TO WORK STRATEGY: TWO YEAR FINDINGS (Aspen Inst. 2003), available at [www.fieldus.org/publications/WTWRpt3.pdf](http://www.fieldus.org/publications/WTWRpt3.pdf) (last visited Nov. 14, 2005). This three-year study of microenterprise and self employment of welfare recipients concludes that "[w]hile self-employment is not a work option that makes sense for most recipients of . . . TANE, there are reasons to believe that it should be a part of a self-sufficiency strategy for some.").
28. *Id.* at 47-49.
29. *Id.* at 55.
30. *The Abilities Fund Reaches an Overlooked Population*, 4 AEO EXCHANGE, Oct.-Dec. 2001, available at [www.microenterpriseworks.org/newsletter/Oct-Dec2001/Oct-Dec2001Web.pdf](http://www.microenterpriseworks.org/newsletter/Oct-Dec2001/Oct-Dec2001Web.pdf) (last visited Nov. 14, 2005).
31. JONES, *supra* note 1, at 75-78.

# NO LONGER IMMUNE?

## Court Opens Door to Cases Claiming Link Between Autism and Vaccine Preservative

WENDY N. DAVIS

**L**IKE ALMOST ALL U.S. CHILDREN born in the 1990s, Robert Edgar Holder and his brother, Matthew Clayton Holder, of Newton County, Miss., received a series of vaccinations to immunize them against childhood diseases.

And, like almost all such vaccinations back then, the injections contained thimerosal, a mercury-based preservative that makes it possible to package vaccines in containers that may be used for more than one dose.

Both Holder children, now 15 and 13, were diagnosed with autism, a complex developmental disability that affects an individual's social interaction and communication.

Recently, however, many scientists have come to believe that thimerosal may cause autism. According to published accounts, a study by an epidemiologist for the federal Centers for Disease Control and Prevention reported in 2001 that thimerosal is linked to the dramatic rise in the number of reported cases of autism.

Since then, more than 4,000 suits have been filed by parents of affected children. This March, plaintiffs may have won the first major victory in a thimerosal case when the New Orleans-based 5th U.S. Circuit Court of Appeals ruled that their lawsuit against three companies that manufactured thimerosal could proceed in federal court. *Holder v. Abbott Laboratories Inc.*, 444 F.3d 383.

The ruling is significant because a federal appeals court apparently for the first time said a suit may bypass a special court set up to resolve liability claims against vaccine manufacturers. Under the 1986 National Childhood Vaccine Injury Act, which created a no-fault system to compensate plaintiffs for injuries caused by vaccines, cases must be routed to the U.S. Court of Federal Claims.

The "vaccine court," as it is called, tries cases without juries and issues damages that are usually far lower than those assessed in regular courts—and are often insufficient to compensate severely injured children, plaintiffs' attorneys say.

However, the 5th Circuit agreed with the Holders' attorney, Jay Kilpatrick of Jackson, Miss., that thimerosal is merely a preservative and not itself a vaccine. "The vaccine



Jay Kilpatrick's suit against thimerosal makers is the first to skip "vaccine court."

act does not bar the Holders' claims against the thimerosal defendants," the 5th Circuit wrote.

"Thimerosal defendants are not vaccine manufacturers, as that is contemplated by the vaccine act statute," Kilpatrick says.

As many as 1.5 million Americans—children and adults—are thought to have autism, according to the Autism Society of America.

While autism is considered a spectrum disorder that affects each individual differently and with varying degrees of severity, the Holders' condition is especially acute, Kilpatrick says.

"They have a very severe case of autism," he says. "Allergies are heightened. They can't go to school." Without intensive help, they won't be able to stay in their parents' home, he adds. Many autistics can function at a high level, Kilpatrick says. "Mine can't."

### 'AN UNNECESSARY PRODUCT'

THE HOLDERS BROUGHT SUIT IN 2002 IN MISSISSIPPI AGAINST a host of defendants—including the doctor who administered the vaccines, the medical centers where they were given, and the pharmaceutical companies that manufactured them.

Along with other plaintiffs, the Holders argue that thimerosal isn't even necessary.

While upholding the lower court's dismissal of several of the Holders' claims, the 5th Circuit ruled that their lawsuit against three companies that manufactured thimerosal—Eli Lilly and Co., Sigma-Aldrich Inc., and Spectrum Chemical Manufacturing Corp.—could proceed in federal court. (Although Abbott was the lead defendant, the company was not included in the remand.)

The court cited its 2004 decision that thimerosal's "sta-

*Continued on page 43*

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tus as a vaccine component no more makes thimerosal a 'vaccine' than does the inclusion of a piston under the hood of an automobile make that object an 'engine.'" *Moss v. Merck & Co.*, 381 F.3d 501. The result, the court said, is that claims against thimerosal manufacturers are not governed by the vaccine act.

That argument has been endorsed by Robert F. Kennedy Jr., an environmental lawyer and co-director at Pace University School of Law's Environmental Litigation Clinic.

In a June 2005 article for *Rolling Stone* magazine, Kennedy condemned the pharmaceutical industry for adding thimerosal to vaccines—a move he decries as a completely unnecessary risk undertaken for no reason other than to save a paltry sum on packaging inoculations.

"The injury was not caused by the vaccine. The injury was caused by the inclusion of an unnecessary product by the pharmaceutical industry," Kennedy says.

While mercury has long been considered a neurotoxin, the potential link between thimerosal in vaccines and autism wasn't widely publicized until the early part of this decade.

In recent years, the possible connection has received a great deal of publicity, including

Kennedy's much-noticed article in *Rolling Stone*. "The story of how government health agencies colluded with Big Pharma to hide the risks of thimerosal from the public is a chilling case study of institutional arrogance, power and greed," Kennedy wrote in the article, "Deadly Immunity."

"If, as the evidence suggests, our public-health authorities knowingly allowed the pharmaceutical industry to poison an entire generation of American children, their actions arguably constitute one of the biggest scandals in the annals of American medicine."

Kennedy says he has filed freedom of information requests seeking records that show the possible link between thimerosal and autism. He has not filed any of the personal injury lawsuits stemming from thimerosal.

Kennedy and other lawyers say the vaccine act was passed in recognition that inoculations, which contain a small dose of live viruses, are inherently dangerous to a small proportion of the population with a very low tolerance to such viruses.

But the defense bar says the cases belong in vaccine court. Attorney Gary J. Spahn, co-chair of the ABA Litigation Section's Products Liability Committee, says that making the distinction between live viruses and other

materials used to manufacture a vaccine is "slicing the bologna pretty thin."

The vaccine act was intended "to protect the folks that get into the business of manufacturing the vaccines," which includes the pharmaceutical companies that put thimerosal in the product, says Spahn, who practices in Richmond, Va. He adds that the policy behind the vaccine act was to encourage pharmaceutical companies to produce vaccines—a policy he says will be defeated if they can be sued for having included a preservative in the vaccines.

Marjorie Powell, senior assistant general counsel of the Pharmaceutical Research and Manufacturers of America, the industry's advocacy group, adds that plaintiffs should prefer vaccine court.

The court is "intended to provide prompt and inexpensive decision-making," similar to workers' compensation hearings. She says plaintiffs don't have to prove causation, plus the process is streamlined and intended to provide consistency.

#### GETTING THEIR CHANCE

PLAINTIFFS LAWYER KILPATRICK, however, says the 5th Circuit decision is the only hope his clients have of getting real relief for their injuries. He says the Holders might have missed the three-year statute of limitations

in vaccine court because they didn't file suit until 2002, shortly after they learned of the possible link between thimerosal and autism. This date was more than three years after the autism symptoms appeared, which is when the clock starts running, Kilpatrick says. "It's a violation of due process for these children not to have any remedy whatsoever."

With thousands of cases filed against thimerosal makers wending their way through the courts, most trial courts have so far agreed with the pharmaceutical industry and held that cases stemming from thimerosal in vaccines belong in vaccine court. (In 2002, Congress passed a rider that stated claims against thimerosal manufacturers must be brought in vaccine court, but that provision was repealed in 2003.)

As for the Holders, they still have an uphill battle in court. Kilpatrick says that, under Mississippi law, they will have to prove which of the three potential manufacturers was responsible for the thimerosal that the Holder children received.

Then, he will have to prove that the thimerosal actually caused the autism—a potentially challenging battle because scientists are divided on that issue. "It's going to be hard," he says. "It's going to be a difficult case." ■

*One lawyer-writer  
alleges that  
"government health  
agencies colluded  
with Big Pharma  
to hide the risks  
of thimerosal."*

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## Essay

### 11. Shut Down, Two Days Into Hearings, by Terry W. Hammond

*"There are lives at stake. Our state governmental policy appears to regard the mentally challenged as just beggars, robbers and thieves. But Hammond's clients include a Katrina evacuee, a Boston University graduate, and other very bright, talented, but mentally ill people. ... Texas has failed miserably." -- Hammond writes about the state-halted hearings into "personal care" homes.*

*Editor's note:* We invited El Paso attorney Terry W. Hammond to write about his investigation into living conditions for mentally and physically challenged people in El Paso and the State of Texas. Hammond was appointed as master in chancery and guardian ad litem for multiple mentally ill clients by El Paso Probate Judge Max Higgs after Higgs had observed repeated psychiatric hospitalizations of residents emanating from the same unlicensed motels, boarding houses and foster homes. Those hearings were shut down by the State of Texas, which argued that the venue in which the hearings were being held was inappropriate. The hearings were in Judge Max Higgs' probate court, and the state argued, in part, that only a district court could call such a hearing.

Some state governments readily accept their responsibility to care for the aged and disabled. Some do so reluctantly. Other must be forced to do so. This is a story about how the state that consistently jockeys for 50th place in health and human services responds to its neediest citizens.

Two years ago, El Paso County Probate Judge Max Higgs appointed me on a number of cases which made national news after case presentations revealed a system in which frail and elderly El Pasoans suffered abuse, neglect, and exploitation even after investigations by Texas Adult Protective Services, a division of the Texas Department of Health and Human Services (HHSC). The cases garnered headlines for months, and Gov. Rick Perry issued an executive order calling for the Office of Inspector General, also a division of HHSC, to conduct a statewide investigation of the agency. The investigation revealed that over 20,000 Texans had been reported three or more times to APS as being abused, neglected or exploited, and no one knew the fate of these people.

The Legislature then began an effort to reform the Adult Protective and Children's Protective Services System in Texas. Notably, El Paso was nowhere near the top of the HHSC regions in the level of harm occurring to elderly and disabled Texans; in fact, there were six regions worse than ours, and only four that were better. In the Spring of 2005, after months testimony and 11th hour negotiations, the Legislature passed a \$34,000,000.00 protective services and guardianship reform bill that attempted to improve the State's protective services and guardianship systems, including certification and standards for guardians.

Clearly, as one legislator commented, the State was committing "malpractice" in its treatment of elderly, vulnerable Texans. This was a statewide problem, and Judge Higgs and I were the ones who initially exposed it.

One of Governor Perry's key aides told a colleague that he wished his office had known about the problem before it hit the national news. The reason why is beginning to become clear.

Just eight months later, in January of 2006, Judge Higgs heard a commitment proceeding on a schizophrenic woman who nearly died at a local motel where the owner and a "liaison" who brought clients to the motel, had gained control of her money, and allegedly failed to

properly feed, clothe, and shelter her. The woman, who had been traveling from Alabama to California by bus, ran out of money and ended up at a local homeless shelter. A caseworker at the homeless shelter referred her to the "liaison." The liaison took her to the motel. A non-profit organization managed by the motel owner became payee for her money, and paid the owner and his partner \$420 of her \$603 monthly Social Security check. According to testimony, the motel owner then proceeded to feed her discarded, rotted convenience store food. The woman lost 60 pounds in six months, was digging in dumpsters for food, and had not changed clothes in nearly two months. She was hanging out of a balcony window when the police were called to take her to the psychiatric hospital.

At that hearing, Higgs appointed me to be a guardian ad litem to represent the best interests of all mentally ill residents of that motel. Judge Higgs also appointed me as a master in chancery to gather evidence about my clients' living conditions in these locations and present it to the Court. A few weeks later, he expanded my appointment to include all residents of a local "boarding home" which was entirely populated with persons with mental illness, primarily schizophrenia, most of whom had been placed there by MHMR or at the recommendation of MHMR. In all, the appointments totaled 27. I agreed to compensation of less than \$400 per case to take the cases to hearing, and engaged in a six-month investigation to determine the quality of care my clients were receiving in these unlicensed facilities and to hold three days of hearings before the Court.

I had lined up about 30 witnesses (to include clients, family members, owners of facilities, and professionals in the community). The hearings began on Tuesday, June 21, and continued until about 10 a.m. on Wednesday, June 22. On Tuesday morning, I was met by a host of opposing counsel who were resisting the subpoenas I had issued, chief of whom was an Assistant Attorney General for the State of Texas who had flown in to El Paso from Austin to quash the subpoenas issued to the director of the El Paso Psychiatric Center and two employees of our local Area Agency on Aging. I personally knew each of these witnesses and had given them a friendly invitation to testify. The subpoenas were not issued until late in the week before the hearings after the Assistant Attorney General advised me they would not appear voluntarily.

The judge took the Attorney General's motion under advisement, and the hearings continued with other witnesses being called to testify. As the hearings entered their tenth hour, the Attorney General's Office filed a mandamus brief, took it to the Court of Appeals, and secured an ex parte order staying the proceedings. Weeks of legal wrangling in the Court of Appeals ensued in which I had to hire two appellate attorneys to represent me. Finally, an agreed order was entered where Judge Higgs excised my appointment as master in chancery, ending a theoretical argument by the Attorney General that I might serve as the judge hearing my own cases presented by me as master in chancery. The hearings were heard in their entirety by Judge Higgs; I only presented evidence.

Before the state stifled the testimony, the primary caretaker at one boarding home testified that 16 people with schizophrenia, mental retardation, major depression, bipolar disorder, and/or dementia had been living in a space of 520 square feet. The evidence revealed the men were sleeping with up to five or six people per 80 square foot room. The walls and locked gates were nine to 10 feet tall. The residents, many of whom had been put there by MHMR, ranged from 21 to 80 years of age. Social Security had appointed the owner of the boarding home as representative payee for some of the residents, and he was paying himself \$450 per month for room and board, leaving them only about \$5 per day to live on. My investigation revealed that numerous neighbors had complained to public officials about the poor care the residents were receiving, including reports of naked residents urinating and defecating in the yard. The 16-plus residents were often left in the care of minor

children. The owner of the boarding home had previously referred to his clients as "rejects," according to newspaper reports.

The evidence also showed that the motel in question was primarily populated with mentally ill residents as well. Most of these residents were referred to the owner by a local homeless shelter. A non-profit company had gained control of the Social Security checks, which normally amounted to no more than \$603 per month, thereby controlling every aspect of their lives. Three of my clients testified that the residents were served rotted food from convenience stores, while the motel owner and his liaison, who was responsible for tending to the residents' personal needs, pocketed almost all of the money. The residents, who again had diagnoses of schizophrenia, depression, and mental retardation, were left to live on \$5 a day. One client said she dug in dumpsters for food because she knew the dumpsters were dumped daily so the food in them could only be one day old.

Police records revealed more than 100 emergency visits at each of these places each year, at a cost to local taxpayers of tens of thousands of dollars. EMS and the fire department were going to each place 20 to 30 times a year, again costing taxpayers. Many required repeated hospitalizations at local hospitals.

The 10 hours of testimony revealed that there was a total failure of any and all governmental entities to properly intervene to prevent suffering of the mentally ill in El Paso and, I suspect, in the entire State of Texas. Under Chapter 247 of the Texas Health and Human Services Code, the State (specifically, ironically, the Texas Attorney General) is responsible for enjoining the operation of illegal "personal care homes" operating as assisted living facilities. However, the State has defined "personal care home" so narrowly that motels, boarding homes, and foster homes dispensing medication, providing transportation, and feeding mentally ill residents is not considered "personal care." The State has allowed the proprietors of these "facilities" to make hundreds of thousands of dollars a year while operating completely unregulated.

Just after the Order staying the hearings was read before an anxious and bewildered audience, the local MHMR director whispered in my ear:

"We've just received information indicating that there are 4000 of these homes around the State caring for 60,000 mentally ill residents." This number was up from 1200 homes just six years ago.

Everyone in the courtroom was in a state of shock. Residents of these homes had shaved, dressed up, and had come to tell the judge about their lives in these places. Local advocates were left wondering what to do next. The first thought in my mind was, "Why is the State shutting us down when they should be shutting down the low lives who are exploiting these Texans?" The cost of taking a more comprehensive, holistic approach to caring for the mentally ill must be a factor here. And...there was a gubernatorial campaign in the works as well.

The Texas Attorney General may have won a fleeting tactical victory in staying the proceedings, or at least in obstructing them. However, the problems still remain. There are lives at stake. Those Texans with mental illness are being stored away in conditions reminiscent of the Whitechapel district in 19th century England.

Our state governmental policy appears to regard the mentally challenged as just beggars, robbers and thieves. But my clients include a Katrina evacuee, a Boston University graduate with a degree in philosophy and a legal education, and other very bright, talented, but

mentally ill people. If, indeed, the most basic function of government is to care for those who cannot care for themselves, Texas has failed miserably.

The custodial role of a guardianship and probate court, and the advocacy that committed legal counsel can provide, have been highlighted in this ongoing struggle to ensure at least a modicum of comfort and care for vulnerable Texans. I have been advised that the Texas Rangers, our elite law enforcement agency in Texas, has been investigating us. I have learned of two APS investigations into my conduct as an attorney and guardian. It is a rather McCarthyesque environment in which I am trying to practice and exist.

But, it seems to me that this is what advocacy is all about. Time will tell if I continue to choose to continue to practice in Texas, or if I find it more enjoyable and fulfilling to work in other jurisdictions. In the meantime, I am interested in finding out if our experience in Texas is unique, or if it is a reflection of where we are as a nation. This is a dialogue that cannot be stayed.

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*Terry W. Hammond is an attorney and partner with the Hammond Townsend Allala Law Firm, which specializes in guardianship, elder and disability law. Mr. Hammond is a past president of the National Guardianship Association and was named as its Executive Director earlier this year. He is a guardianship mediator, certified by the National Center for Social Gerontology, and is a Registered Guardian as certified by the National Guardianship Foundation.*

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**HEALTH CARE VALUES HISTORY FORM**

NAME: \_\_\_\_\_

DATE: \_\_\_\_\_

If someone assisted you in completing this form, please fill in his or her name, address, and relationship to you.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Relationship: \_\_\_\_\_

The purpose of this form is to assist you in thinking about and writing down what is important to you about your health and medical care. If you should at some time become unable to make health care decisions for yourself, your thoughts as expressed on this form may help others make a decision for you in accordance with what you would have chosen.

The first section of this form asks whether you have already expressed your wishes concerning medical treatment through either written or oral communications and if not, whether you would like to do so now. The second section of this form provides an opportunity for you to discuss your values, wishes, and preferences in a number of different areas, such as your personal relationships, your overall attitude toward life, and your thoughts about illness.

This form is not a legal document, although it may be used as evidence of your health care values in a legal proceeding.

## WHY A HEALTH CARE VALUES HISTORY FORM?

The Health Care Values History Form recognizes that health care decisions we make for ourselves are based on those beliefs, preferences and values that matter most to us: How do we feel about independence and control? About pain, illness, dying and death? What in life gives us pleasure? Sorrow? A discussion of these and other values can provide important information for those who might, in the future, have to make medical decisions for us when we are no longer able to do so.

Further, a discussion of the questions asked on the Health Care Values History Form can provide a solid basis for families, friends, physicians and others when making such health care decisions on your behalf should you become unable to do so yourself. By talking about such issues ahead of time, family disagreements may be minimized. And when such decisions do need to be made, the burden of responsibility may be lessened because others feel confident of your wishes.

## HOW DO I FILL OUT THE HEALTH CARE VALUES HISTORY FORM?

Section 1 allows you to record both written and oral instructions you might already have prepared. Simply answer the questions. If you have not yet written or talked about these issues, you might wait to complete this section at a later date, perhaps after you have completed Section 2.

Section 2 asks a number of questions about issues such as: Your attitude toward your health; Your feelings about your health care providers; Your thoughts about independence and control; Personal Relationships; Your overall attitude toward life and preferences for life activities; Your attitude toward illness/dying/death; Your religious background and beliefs; Your living environment and daily routine; Your attitude toward finances.

There are a number of ways in which you might begin to answer these questions. Perhaps you would like to write out some of you own thoughts before you talk with anyone else. Or you might ask family and friends to come together and talk about your, and their, responses to the questions.

Often simply making copies of the Health Care Values History Form available to others is enough to get people talking about a subject that, for many of us, is difficult and painful to consider. The most important thing to remember is that **it is easier to talk about these issues BEFORE a health care crisis occurs**. Feel free to add questions and comments of your own to those already provided.

## **WHAT SHOULD I DO WITH MY COMPLETED HEALTH CARE VALUES HISTORY FORM?**

Make certain that all those who might be involved in future medical decisions made on your behalf are aware of your wishes: family, friends, physicians and other health care providers, your lawyer, your Pastor. If appropriate, provide written copies to these people. But remember that each of us continues to grow and change, and so the Health Care Values History Form should be discussed and updated fairly regularly, as preferences and values evolve. Consider attaching a copy of it to your Patient Advocate Designation or Durable Power of Attorney or filing the Health Care Values History Form with your important medical papers.

## **WHO SHOULD CONSIDER PREPARING A HEALTH CARE VALUES HISTORY FORM?**

*Everyone.* While it has been customary to focus on older people, it is just as important that younger people discuss these issues and make their wishes known. Often some of the most difficult medical decisions must be made on behalf of these younger patients. If they had talked with families and friends, these decision makers could feel reassured they were following the patient's wishes.

**People with disabilities can also address their values as to medical care and treatment. Family members, advocates, or others can assist the person in filling out a Health Care Values History Form.**

\*\*\*\*\*

We hope this Health Care Values History Form is of help to you, your families and friends. Many people have commented that it is important to reflect not so much on "How I want to die," but rather on "**How I want to LIVE until I die.**"

Sincerely,

Hafeli Staran Hallahan Christ & Dudek, P.C.

**SECTION 1**

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**A. WISHES CONCERNING SPECIFIC MEDICAL PROCEDURES**

If you have already expressed your wishes, either written or orally, concerning any of the following medical procedures, please complete this information. If you have not, please indicated your preferences regarding these procedures. *(Note: You may also wish to consider completing a Patient Advocate Designation, which is a legal document that allows someone you name to make decisions on your behalf in accordance with your preferences if you are unable to. Please ask us for more information!)*

**Organ Donation**

To whom expressed: \_\_\_\_\_

If oral, when? \_\_\_\_\_

If written, when? \_\_\_\_\_

Documentation location: \_\_\_\_\_

Comments/Preferences: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Kidney Dialysis**

To whom expressed: \_\_\_\_\_

If oral, when? \_\_\_\_\_

If written, when? \_\_\_\_\_

Document location: \_\_\_\_\_

Comments/Preferences: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Cardiopulmonary Resuscitation (CPR)**

To whom expressed: \_\_\_\_\_

If oral, when? \_\_\_\_\_

If written, when? \_\_\_\_\_

Document location: \_\_\_\_\_

Comments/Preferences: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Respirators**

To whom expressed: \_\_\_\_\_

If oral, when? \_\_\_\_\_

If written, when? \_\_\_\_\_

Document location: \_\_\_\_\_

Comments: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

**Artificial Nutrition**

To whom expressed: \_\_\_\_\_

If oral, when? \_\_\_\_\_

If written, when? \_\_\_\_\_

Document location: \_\_\_\_\_

Comments: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

**Artificial Hydration**

To whom expressed: \_\_\_\_\_

If oral, when? \_\_\_\_\_

If written, when? \_\_\_\_\_

Document location: \_\_\_\_\_

Comments: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

**B. GENERAL COMMENTS**

Do you wish to make any general comments about the information you provided in this section?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**SECTION 2**

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**A. YOUR OVERALL ATTITUDE TOWARD YOUR HEALTH**

1. How would you describe your current health status? If you currently have any medical problems, how would you describe them? \_\_\_\_\_

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2. If you have current medical problems, in what ways, if any, do they affect your ability to function? \_\_\_\_\_

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3. How do you feel about your current health status? \_\_\_\_\_

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4. How well are you able to meet the basic necessities of life—eating, food preparation, sleeping, personal hygiene, etc.? \_\_\_\_\_

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5. Do you wish to make any general comments about your overall health? \_\_\_\_\_

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**B. YOUR PERCEPTION OF THE ROLE OF YOUR DOCTOR AND OTHER HEALTH CAREGIVERS**

1. Do you like your doctors? \_\_\_\_\_

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2. Do you trust your doctors? \_\_\_\_\_

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3. What characteristics are important to you regarding your doctors or other health care providers? What characteristics or values makes you want to change doctors or other health care providers?

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4. Do you think your doctors should make the final decision concerning any treatment you might need? \_\_\_\_\_

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5. How do you relate to your caregivers, including nurses, therapists, chaplains, social workers, etc.?

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6. Do you wish to make any general comments about your doctor and other health caregivers, and preferences regarding medical treatment (e.g., use of minimal medications)?

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**C. YOUR THOUGHTS ABOUT INDEPENDENCE AND CONTROL**

1. How important is independence and self-sufficiency in your life? Are there certain areas in your life that are more important than others regarding independence and self-sufficiency (e.g., finances, employment, independent living)? \_\_\_\_\_

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2. If you were to experience decreased physical and mental abilities, how would that affect your attitude toward independence and self-sufficiency? \_\_\_\_\_

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3. Do you wish to make any general comments about the value of independence and control in your life? \_\_\_\_\_

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**D. YOUR PERSONAL RELATIONSHIPS**

1. Do you expect that your friends, family and/or others will support your decisions regarding medical treatment you may need now or in the future? \_\_\_\_\_

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2. Have you made any arrangements for your family or friends to make medical treatment decisions on your behalf? If so, who has agreed to make decisions for you and in what circumstances? \_\_\_\_\_

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3. What, if any, unfinished business from the past are you concerned about (e.g., personal and family relationships, business and legal matters)? \_\_\_\_\_

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4. What role do your friends and family play in your life? \_\_\_\_\_

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5. Do you wish to make any general comments about the personal relationships in your life? \_

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**E. YOUR OVERALL ATTITUDE TOWARD LIFE AND LIFE ACTIVITIES**

1. Are you happy to be alive? \_\_\_\_\_

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2. Do you feel that life is worth living? \_\_\_\_\_

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3. What activities do you enjoy (e.g., hobbies, watching television)? Describe the activities in detail (e.g. type of television shows)\_\_\_\_\_

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4. What type of music do you enjoy? It is an important part of your life? \_\_\_\_\_

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5. What accomplishments in your life are you most proud of?

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6. How important is your current or past career path(s) to you? What do/did you do regarding employment? \_\_\_\_\_

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7. How satisfied are you with what you have achieved in your life? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

8. What makes you laugh/cry? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

9. What do you fear most? What frightens or upsets you? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

10. What goals do you have for the future?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

11. Do you wish to make any general comments about your attitude toward life and/or your life activities? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**F. YOUR ATTITUDE TOWARD ILLNESS, DYING AND DEATH**

1. What will be important to you when you are dying (e.g., physical comfort, no pain, family members present, etc.)? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

2. Where would you prefer to die? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

3. What is your attitude toward death? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

4. How do you feel about the use of life-sustaining measures in the face of :  
Terminal illness? \_\_\_\_\_  
Permanent coma? \_\_\_\_\_  
Irreversible chronic illness (e.g., Alzheimer's disease)? \_\_\_\_\_  
\_\_\_\_\_

5. Do you wish to make any general comments about your attitude toward illness, dying, and death? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**G. YOUR RELIGIOUS BACKGROUND AND BELIEFS**

1. What is your religious background? What is the level of your involvement in religious activities? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

2. How do your religious beliefs affect your attitude toward serious or terminal illness? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

3. Does your attitude toward death find support in your religion? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

4. How does your faith community, church, or synagogue view the role of prayer or religious sacraments in an illness? \_\_\_\_\_

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5. Do you wish to make any general comments about your religious background and beliefs? \_\_\_\_\_

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## **H. YOUR LIVING ENVIRONMENT AND DAILY ROUTINE**

1. What has been your living situation over the last 10 years (e.g., lived alone, lived with others, etc.)? What type of living situation do you prefer? \_\_\_\_\_

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2. How difficult is it for you to maintain the kind of environment for yourself that you find comfortable? Does any illness or medical problem you have now mean that it will be harder in the future? \_\_\_\_\_

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3. Do you wish to make any general comments about your current living environment? \_\_\_\_\_

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## **SUGGESTIONS FOR USE**

After you have completed this form, you may wish to provide copies to your doctors and other health caregivers, your family, your friends, and your attorney. If you have a Patient Advocate Designation, you may wish to attach a copy of this form to those documents.

*This document was drafted by Patricia E. Kefalas Dudek, Esq.*

**PATIENT ADVOCATE DESIGNATION**  
**FOR MENTAL HEALTH TREATMENT**

**NOTICE TO PATIENT**

As the “Patient” you are using this Patient Advocate Designation for Mental Health Treatment to grant powers to another individual designated as your Patient Advocate. Your Patient Advocate has specific authority to make mental health decisions on your behalf. This authority is triggered, if and only if, you are unable to participate in your mental health decisions. The determination if you can participate in your mental health decisions will be made by your physician and mental health professional. This authorization is also intended to be a specific release of your mental health information to your Patient Advocate so that they can make a determination if they in fact are required to serve. You have the right to take back this designation and revoke it at any time provided that you are of sound mind, unless you have chosen to waive this right. The intended purpose of this Patient Advocate Designation for Mental Health Treatment is to address issues of your mental health treatment and your preferences. If at any time you or your Patient Advocate do not understand this Patient Advocate Designation for Mental Health Treatment, you should ask your lawyer to explain it. You should complete a Health Care Values History Form and provide a copy to your Patient Advocate.

I, [CLIENT NAME] (the “Patient”) of [CLIENT CITY], Michigan, being of sound mind, full age and under no duress or influence, do hereby make the following Patient Advocate Designation for Mental Health Treatment pursuant to MCL 700.5506.

1. ***Designation of Patient Advocate.*** I hereby designate [PA NAME], of [PA CITY], Michigan, as my Patient Advocate for Mental Health Treatment to exercise powers concerning my mental health care and to make mental health treatment decisions for me. If [PA NAME] does not accept, resigns, is incapacitated, dies, or is otherwise unwilling to act, I appoint [SPA 1 NAME] of [SPA 1 CITY], Michigan, as my Successor Patient Advocate for Mental Health Treatment. If [SPA 1 NAME] does not accept, resigns, is incapacitated, dies, or is otherwise unwilling to act, I appoint [SPA 2 NAME] of [SPA 2 CITY], Michigan, as my Successor Patient Advocate/

If my Patient Advocate is unable to act after a reasonable effort has been made to contact that person, my Successor Patient Advocate is authorized to act until my Patient Advocate becomes available.

2. ***Effective Date and Durability.*** This document is intended to create a Power of Attorney pursuant to MCL 700.5506 that may be exercised only when I am unable to participate in mental health treatment decisions. My physician and a mental health professional, after examining me, shall determine whether I am able to participate in mental health treatment decisions. I wish the mental health professional to be (*select one*):

- \_\_\_\_\_ A physician who is licensed to practice medicine or osteopathic medicine and surgery in Michigan.
- \_\_\_\_\_ A licensed or limited licensed, psychologist practicing in Michigan.
- \_\_\_\_\_ A registered professional nurse licensed to practice in Michigan.
- \_\_\_\_\_ A social worker registered as a certified social worker, or after July 1, 2005, “a licensed master’s social worker”) licensed to practice in Michigan.
- \_\_\_\_\_ A physician’s assistant licensed to practice in Michigan.
- \_\_\_\_\_ A licensed professional counselor under the Public Health Code.

I designate the following individual(s) to make this determination (name and professional):

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Any determination that I am unable to participate in mental health treatment decisions, to do so must be in writing; made part of my mental health treatment records and reviewed at least annually. If I regain my ability to participate in mental health treatment decisions, my designation of a Patient Advocate for mental health treatment is suspended but may become effective again if I am subsequently determined to be unable to participate in medical decisions in accordance with the procedure set forth above. This Patient Advocate Designation for Mental Health Treatment shall not be affected by my disability and shall continue in effect until my death or until I revoke it in writing.

3. ***Powers of Patient Advocate.*** My Patient Advocate for Mental Health Treatment shall be considered my “Personal Representative” for purposes of the Privacy Rule issued by the U.S. Department of Health and Human Services and required by the Privacy Rules of the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”), and may have full access to my medical and mental health records, including any psychotherapy notes. I grant to my Patient Advocate full power and authority to make decisions for me regarding my mental health treatment and care. I intend for my Patient Advocate to have the same authority to exercise all of my rights as a citizen, including, but not limited to, the right of liberty and self-determination that I have while I am competent, including those specified in the Michigan Mental Health Code, MCL 330.1100 et seq.

In exercising this authority, my Patient Advocate shall follow my expressed wishes, either written or oral, regarding my mental health treatment. In making any decision, my Patient Advocate should first try to discuss the proposed decision with me to determine my desires if I am able to communicate in any way. If my Patient Advocate cannot determine the choice I would want based on my past written or oral statements, or if this Patient Advocate Designation for Mental Health Treatment does not contemplate the particular mental health treatment decision with which my Patient Advocate is faced, then my Patient Advocate shall choose for me

based on what my Patient Advocate believes to be in my best interest and is the least restrictive treatment intervention in accordance with my diagnosis and severity of symptoms, and in accordance with Michigan's Mental Health Code, MCL §330.1100 et seq.

Unless specifically limited by me, by either written or oral statements, my Patient Advocate shall have the power to obtain, consent to, and/or refuse treatment on my behalf to ensure I receive proper and adequate mental health care and treatment that is in my best interest and is the least restrictive treatment intervention, including arranging appropriate residential placement, and making payment arrangements to secure the necessary treatment. My Patient Advocate for Mental Health Treatment shall also work with any Representative Payee for any government benefits that I may be entitled to, Conservator, Guardian of my Estate, Agent named under a Durable Power of Attorney, Patient Advocate for medical decisions, or Trustee of a trust established for my benefit, if necessary to fulfill these responsibilities identified herein.

4. ***Specific Grants of Authority.*** My Patient Advocate shall have the following authority regarding my mental health treatment (*Optional*):

a. ***Inpatient Psychiatric Hospitalization.*** My Patient Advocate (*select one*):

\_\_\_\_\_ shall

\_\_\_\_\_ shall not

have the power to consent to inpatient psychiatric hospitalization and treatment, if it is in my best interest and is the least restrictive treatment, to protect my safety and/or the safety of others, and if in accordance with the civil admission and discharge procedures set forth in Chapter Four of the Michigan Mental Health Code.

However, if I am hospitalized as a formal voluntary patient under an application executed by my Patient Advocate, I retain the right to terminate the hospitalization in accordance with MCL §330.1419.

b. ***Forced Administration of Psychiatric Medications.*** My Patient Advocate (*select one*):

\_\_\_\_\_ shall

\_\_\_\_\_ shall not

have the power to consent to forced administration of psychiatric medications, if it is in my best interest and is the least restrictive treatment to protect my safety and/or the safety of others.

c. ***Electroconvulsive Therapy.*** My Patient Advocate (*select one*):

\_\_\_\_\_ shall

\_\_\_\_\_ shall not

have the power to consent to electroconvulsive therapy, or a procedure intended to produce convulsions or coma, in accordance with MCL § 330.1717 of the Michigan Mental Health Code, if it is in my best interest and is the least restrictive treatment to protect my safety and/or the safety of others.

5. ***Waiver of Right to Revoke.*** Regarding the revocation of this Patient Advocate Designation for Mental Health treatment (*select one*):

\_\_\_\_\_ I do not waive the right to revoke the powers granted in this Patient Advocate Designation regarding mental health treatment decisions. The powers granted to my Patient Advocate to make mental health treatment decisions will be terminated upon the communication of my intent to revoke.

\_\_\_\_\_ I do waive the right to revoke the powers granted in this Patient Advocate Designation regarding mental health treatment decisions. This waiver does not affect the rights afforded to me to terminate formal voluntary hospitalization under MCL §330.1419. Furthermore, if I communicate at a later time that I wish to revoke this Patient Advocate Designation for mental health treatment while I am deemed unable to participate in decisions regarding mental health treatment, and I am receiving mental health treatment at that time, mental health treatment shall not continue for more than thirty (30) days. I understand that upon termination of the mental health treatment after thirty (30) days, one of the following may occur:

- a. No further treatment will be necessary;
- b. Assistant outpatient treatment is ordered by a court of competent jurisdiction; or,
- c. Involuntary psychiatric hospitalization is ordered by a court of competent jurisdiction under Michigan Mental Health Code, MCL 330.1434 et seq.

6. ***Binding Effect on Mental Health Professionals.*** A mental health professional who provides mental health treatment to a patient shall comply with my wishes as expressed in writing or orally, or in this Patient Advocate Designation for Mental Health Treatment. However, I acknowledge that under MCL §700.5511(4), the mental health professional is not bound to follow that desire if one or more of the following apply:

- a. In the opinion of the mental health professional, compliance is not consistent with generally accepted community practice standards of treatment;
- b. The treatment requested is not reasonably available;
- c. Compliance is not consistent with applicable law;

- d. Compliance is not consistent with court ordered treatment; or,
- e. In the opinion of the mental health professional, there is a psychiatric emergency endangering my life or another individual and compliance is not appropriate under the circumstances.

7. **Conflicts with Patient Advocate for Medical Treatment.** I (select one) \_\_\_\_\_ have/ \_\_\_\_\_ have not previously executed a Patient Advocate Designation for Medical Treatment on \_\_\_\_\_ (date, if applicable).

If there is disagreement between my Patient Advocate for Mental Health Treatment and my Patient Advocate for Medical Care regarding authorization of treatment which affects both my medical status and mental health, instructions from the following shall receive priority (select one if applicable):

- \_\_\_\_\_ Patient Advocate for Mental Health Treatment, or
- \_\_\_\_\_ Patient Advocate for Medical Care

Furthermore, if a dispute arises as to whether the course of treatment which affects both my medical and mental health status is in my best interest, my Patient Advocate identified above shall obtain the advice from \_\_\_\_\_ to determine the course of treatment. If this conflict is not resolved, then my Patient Advocate for either Mental Health Treatment or Health Care reserves the right to petition the court for instructions.

8. **Nomination of Guardian.** If a guardian of my person is necessary, I nominate (select one)

- \_\_\_\_\_ Patient Advocate for Mental Health Treatment, or
- \_\_\_\_\_ Patient Advocate for Medical Care

to serve as my guardian. If this nomination conflicts with my Patient Advocate Designation for medical treatment decisions previously executed on \_\_\_\_\_, this nomination shall control.

9. **Third Party Reliance.** For the purpose of inducing any and all persons connected with the administration of my mental health care or the implementation of this Patient Advocate Designation for Mental Health Treatment, I represent, warrant and agree that if this document is revoked, modified or amended, I and my estate, heirs, successors and assigns will hold any person harmless from any loss suffered or liability incurred as a result of such person acting in good faith upon the instructions of the Patient Advocate prior to the receipt by such person of actual notice of such revocation, modification or amendment, provided such person's actions are not otherwise invalid or unenforceable.

10. **No Compensation.** My Patient Advocate shall not be entitled to compensation for services performed under this Patient Advocate Designation for Mental Health Treatment, but shall be entitled to reimbursement for actual and necessary expenses incurred as a result of

carrying out his/her authority, rights and responsibilities pursuant to this Patient Advocate Designation for Mental Health Treatment.

11. ***Revocation of Prior Patient Advocate Designations for Mental Health Treatment.*** I revoke any prior Patient Advocate Designations or Durable Powers of Attorney which relate to mental health care that I may have executed to the extent that, and only to the extent that, they grant powers and authority within the scope of the powers granted to the Patient Advocate appointed herein. Nothing in this paragraph shall be deemed to revoke any prior Patient Advocate Designations or Durable Powers of Attorney which relate to health or medical care previously executed by me. Nothing in this paragraph shall be deemed to revoke any portion of a certain Durable Power of Attorney executed by me on this date.

12. ***Separability.*** As required under MCL §700.5513, if a provision of this Patient Advocate Designation for Mental Health Treatment conflicts with the Michigan Mental Health Code, the Michigan Mental Health Code shall control. Furthermore, if any provision of this Patient Advocate Designation for Mental Health Treatment shall be declared invalid or unenforceable under applicable law, that provision shall not affect the other provisions hereof, and this Patient Advocate Designation for Mental Health Treatment shall be construed as if such invalid or unenforceable provision(s) were omitted.

13. ***Binding Effect on Subsequent Disability or Incapacity.*** This Patient Advocate Designation shall not be affected by any subsequent disability or incapacity that I may suffer and is intended to be fully binding, without prior court intervention or approval, to the fullest extent provided by MCL 700.5506. **I direct that this Patient Advocate Designation for Mental Health Treatment be made part of my mental health treatment record of the mental health professional providing treatment, the community mental health services program or hospital providing mental health services, and, if applicable, with the facility where I am located. This Patient Advocate Designation for Mental Health Treatment shall also be made part of my medical records, along with my Patient Advocate Designation for medical decisions, including with my attending physician, and the hospital where I am receiving treatment.**

14. ***Governing Law.*** This Patient Advocate Designation for Mental Health Treatment shall be subject to and governed by the laws of the State of Michigan. However, I intend for this Patient Advocate Designation for Mental Health Treatment to be honored in any jurisdiction where it is presented and for such jurisdiction to refer to Michigan law to interpret and determine its validity and enforceability.

15. ***Photographic Copies.*** Photographic or other facsimile reproductions of this executed Patient Advocate Designation for Mental Health Treatment may be made and delivered by my Patient Advocate, and may be relied upon by any person to the same extent as though the copy were an original. Anyone who acts in reliance upon any representation or certificate of my Patient Advocate, or upon a reproduction of this Patient Advocate Designation for Mental Health Treatment, shall not be liable for permitting my Patient Advocate to perform any act pursuant to this power.

IN WITNESS WHEREOF, I have signed and delivered this *Patient Advocate Designation for Mental Health Treatment* this \_\_\_\_\_ day of \_\_\_\_\_, 2006.

\_\_\_\_\_  
[CLIENT NAME]

**AFFIDAVIT of WITNESSES**

I declare that [CLIENT NAME] (the “Patient”) signed or acknowledged this Patient Advocate Designation for Mental Health Treatment in my presence, and that the Patient appears to be of sound mind and under no duress, fraud or undue influence. I am at least eighteen (18) years of age and I am not the person appointed as Patient Advocate by this Patient Advocate Designation for Mental Health Treatment, nor am I the Patient’s physician, an employee of the Patient’s life or health insurance provider, or an employee of the health care facility or home for the aged where the Patient resides, or of a community mental health services program or hospital that is providing mental health services to the Patient. Further, I declare that I am not the Patient’s spouse, parent, child, grandchild, sibling, or presumptive heir; and, to the best of my knowledge, I am not entitled to any part of the Patient’s estate under a Will now existing or by operation of law.

WITNESSES:

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name

\_\_\_\_\_  
Name

\_\_\_\_\_  
Address

\_\_\_\_\_  
Address

\_\_\_\_\_

\_\_\_\_\_

**AUTHORIZATION TO RELEASE PROTECTED HEALTH INFORMATION**

On \_\_\_\_\_, 2006, I signed a *Patient Advocate Designation for Mental Health Treatment* naming [PA NAME] as my Patient Advocate and [SPA 1 NAME] or [SPA 2 NAME] as Successor Patient Advocate. It is important for them to be fully aware of my mental health situation so they can make mental health treatment decisions affairs on my behalf if necessary. For that reason, I sign this authorization.

In accordance with the Privacy Rules of the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”), I authorize \_\_\_\_\_, or any other physician or mental health professional to release to my nominated Patient Advocate and/or Successor Patient Advocate any protected health information for the purpose of determining whether I am unable to participate in mental health treatment decisions.

This authorization expires upon notice that my Patient Advocate Designation for Mental Health Treatment noted above has been revoked or upon notice that I have specifically revoked this authorization. Otherwise, the authorization continues to be valid.

I recognize that I have a legal right to revoke this authorization at any time in writing by sending a notice to that effect to my treating physician or mental health professional.

I recognize that whether or not I sign this authorization has no effect on treatment, payment, enrollment or eligibility for benefits.

I recognize that any information used or disclosed pursuant to this authorization may be subject to redisclosure by the recipient and no longer protected under HIPAA.

Dated: \_\_\_\_\_  
[CLIENT NAME]

## NOTICE TO PATIENT ADVOCATE

The intended purpose of this *Patient Advocate Designation for Mental Health Treatment* is to address issues related to the Patient's mental health. As the Patient Advocate you are given power under this Patient Advocate Designation to make decisions regarding mental health treatment according with the terms of this Patient Advocate Designation. The Patient directs use your best effort to fulfill your duties under this Patient Advocate Designation consistent the Patient's "Values History Form." The Patient desires that you have a copy of such form. If you do not have a copy of this form please request one from the Patient's attorney who has been authorized to provide you a copy.

This authority is triggered, if and only if, one physician and one mental health professional determines the Patient is unable to participate in these mental health treatment decisions. The Patient also specifically authorized the release of the Patient's mental health treatment information to you so that you may obtain information from the physician and mental health professional and determine if you are required to serve. If at any time you do not understand this *Patient Advocate Designation for Mental Health Treatment* or your duties under it, you should ask a lawyer to explain it to you. The Patient authorized you to contact, confer with and hire the Patient's attorney who drafted the Patient Advocate Designation for Mental Health Treatment even if the information communicated between you and the Patient's Attorney would otherwise be confidential or privileged.

By law, you cannot receive compensation for executing your duties as Patient Advocate, from the individual's funds or from any other third parties. You may, however receive reimbursement for actual and necessary expenses paid out of your own funds on behalf of the individual in carrying out your duties and responsibilities as Patient Advocate (e.g., copying fees for mental health treatment records, patient co-pays).

Please also note that although the guidelines and restrictions, as listed in the *Acceptance of Patient Advocate* may not be applicable to your authority or powers granted as a Patient Advocate for Mental Health Treatment, these guidelines and restrictions must be provided to you by law under MCL § 700.5507(4).

Drafted by:  
Patricia E. Kefalas Dudek (P46408)  
BEIER HOWLETT, P.C.  
200 E. Long Lake Road, Suite 110  
Bloomfield Hills, MI 48304-2361  
Telephone: (248) 645-9400

**ACCEPTANCE OF PATIENT ADVOCATE DESIGNATION**

I, [PA NAME], of [PA CITY], Michigan, acknowledge that I have received a copy of the attached Patient Advocate Designation for Mental Health Treatment and do hereby agree to serve as the Patient Advocate for [CLIENT NAME] (the "Patient") in accordance with both the terms and conditions set forth in the Patient Advocate Designation for Mental Health Treatment and the following guidelines and restrictions:

1. This patient advocate designation is not effective unless the patient is unable to participate in decisions regarding the patient's medical or mental health, as applicable. If this patient advocate designation includes the authority to make an anatomical gift the authority remains exercisable after the patient's death.

2. A Patient Advocate shall not exercise powers concerning the Patient's care, custody, and medical or mental health treatment that the Patient, if the Patient were able to participate in the decision, could not have exercised on his or her own behalf.

3. This Designation cannot be used to make a medical or mental health treatment decision to withhold or withdraw treatment from a Patient who is pregnant that would result in the pregnant Patient's death.

4. A Patient Advocate may decide to withhold or withdraw treatment that would allow the Patient to die only if the Patient has expressed in a clear and convincing manner that the Patient Advocate is authorized to make such a decision and that the Patient acknowledges that such a decision could or would allow the Patient's death.

5. A Patient Advocate shall not receive compensation for the performance of his or her authority, rights, and responsibilities, but a Patient Advocate may be reimbursed for actual and necessary expenses incurred in the performance of his or her authority, rights, and responsibilities.

6. A Patient Advocate shall act in accordance with the standards of care applicable to fiduciaries when acting for the Patient and shall act consistent with the Patient's best interests. The known desires of the Patient expressed or evidenced while the Patient is able to participate in mental health treatment decisions are presumed to be in the Patient's best interests.

7. The Patient may revoke his or her designation at any time and in any manner sufficient to communicate an intent to revoke.

8. The Patient may waive his or her right to revoke this Patient Advocate Designation as to the power to make mental health treatment decisions, and if such a waiver is made, his or her ability to revoke as to certain treatment will be delayed for 30 days after the patient communicates his or her intent to revoke.

9. A Patient Advocate may revoke his or her acceptance to the designation at any time and in any manner sufficient to communicate an intent to revoke.

10. A Patient admitted to a health facility or agency has the rights enumerated in MCL 333.20201.

If I am unable to act after reasonable efforts to contact me, I delegate my authority to the Successor Patient Advocate that the Patient has designated, in the order designated. The Successor Patient Advocate is authorized to act until I become available. If I act as Successor, I acknowledge that my authority ends when any higher-ranking patient advocate becomes available.

IN WITNESS WHEREOF, I have executed this *Acceptance of Patient Advocate Designation for Mental Health Treatment* for [CLIENT NAME] this \_\_\_\_ day of \_\_\_\_\_, 2006.

\_\_\_\_\_  
[PA NAME]

**AUTHORIZATION TO RELEASE PROTECTED HEALTH INFORMATION**

On \_\_\_\_\_, 2006, I signed an *Acceptance of Patient Advocate Designation for Mental Health Treatment* to act as Patient Advocate for [CLIENT NAME].

I therefore authorize any covered entity under HIPAA to disclose protected health information about me for the purpose of determining my capacity to act as Patient Advocate. I hereby voluntarily waive any physician-patient privilege or psychiatrist-patient privilege that may exist in my favor, and I hereby authorize physicians to examine me and disclose my physical or mental condition in order to determine my incapacity or capacity for purposes of acting in the role of agent according to the terms of this document.

This authorization expires upon notice that the *Patient Advocate Designation for Mental Health Treatment* executed by \_\_\_\_\_ has been revoked or upon notice that I have specifically revoked this authorization. Otherwise, the authorization continues to be valid.

I recognize that I have a legal right to revoke this authorization at any time in writing by sending a notice to that effect to my treating physician or mental health professional.

I recognize that whether or not I sign this authorization has no effect on treatment, payment, enrollment or eligibility for benefits.

I recognize that any information used or disclosed pursuant to this authorization may be subject to redisclosure by the recipient and no longer protected under HIPAA.

Dated: \_\_\_\_\_

\_\_\_\_\_  
[PA NAME]

## NOTICE TO PATIENT ADVOCATE

The intended purpose of this Patient Advocate Designation for Mental Health Treatment is to address issues related to the Patient's mental health. As the Patient Advocate you are given power under this Patient Advocate Designation to make decisions regarding mental health treatment according with the terms of this Patient Advocate Designation. The Patient directs use your best effort to fulfill your duties under this Patient Advocate Designation consistent the Patient's "Mental Health Care Values History Form." The Patient desires that you have a copy of such form. If you do not have a copy of this form please request one from the Patient's attorney who has been authorized to provide you a copy.

This authority is triggered, if and only if, one physician and one mental health professional determines the Patient is unable to participate in these mental health treatment decisions. The Patient also specifically authorized the release of the Patient's mental health treatment information to you so that you may obtain information from the physician and mental health professional and determine if you are required to serve. If at any time you do not understand this Patient Advocate Designation for Mental Health Treatment or your duties under it, you should ask a lawyer to explain it to you. The Patient authorized you to contact, confer with and hire the Patient's attorney who drafted the Patient Advocate Designation for Mental Health Treatment even if the information communicated between you and the Patient's Attorney would otherwise be confidential or privileged.

By law, you cannot receive compensation for executing your duties as Patient Advocate, from the individual's funds or from any other third parties. You may, however receive reimbursement for actual and necessary expenses paid out of your own funds on behalf of the individual in carrying out your duties and responsibilities as Patient Advocate (e.g., copying fees for mental health treatment records, patient co-pays).

Please also note that although the guidelines and restrictions, as listed in the *Acceptance of Patient Advocate* may not be applicable to your authority or powers granted as a Patient Advocate for Mental Health Treatment, these guidelines and restrictions must be provided to you by law under MCL § 700.5507(4).

Drafted by:  
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200 E. Long Lake Road, Suite 110  
Bloomfield Hills, MI 48304-2361  
Telephone: (248) 645-9400

**ACCEPTANCE OF SUCCESSOR PATIENT ADVOCATE DESIGNATION**

I, [SPA 1 NAME], of [SPA 1 CITY], Michigan, acknowledge that I have received a copy of the attached Patient Advocate Designation for Mental Health Treatment and do hereby agree to serve as the Patient Advocate for [CLIENT NAME] (the "Patient") in accordance with both the terms and conditions set forth in the Patient Advocate Designation for Mental Health Treatment and the following guidelines and restrictions:

1. This patient advocate designation is not effective unless the patient is unable to participate in decisions regarding the patient's medical or mental health, as applicable. If this patient advocate designation includes the authority to make an anatomical gift the authority remains exercisable after the patient's death.

2. A Patient Advocate shall not exercise powers concerning the Patient's care, custody, and medical or mental health treatment that the Patient, if the Patient were able to participate in the decision, could not have exercised on his or her own behalf.

3. This Designation cannot be used to make a medical or mental health treatment decision to withhold or withdraw treatment from a Patient who is pregnant that would result in the pregnant Patient's death.

4. A Patient Advocate may decide to withhold or withdraw treatment that would allow the Patient to die only if the Patient has expressed in a clear and convincing manner that the Patient Advocate is authorized to make such a decision and that the Patient acknowledges that such a decision could or would allow the Patient's death.

5. A Patient Advocate shall not receive compensation for the performance of his or her authority, rights, and responsibilities, but a Patient Advocate may be reimbursed for actual and necessary expenses incurred in the performance of his or her authority, rights, and responsibilities.

6. A Patient Advocate shall act in accordance with the standards of care applicable to fiduciaries when acting for the Patient and shall act consistent with the Patient's best interests. The known desires of the Patient expressed or evidenced while the Patient is able to participate in mental health treatment decisions are presumed to be in the Patient's best interests.

7. The Patient may revoke his or her designation at any time and in any manner sufficient to communicate an intent to revoke.

8. The Patient may waive his or her right to revoke this Patient Advocate Designation as to the power to make mental health treatment decisions, and if such a waiver is made, his or her ability to revoke as to certain treatment will be delayed for 30 days after the patient communicates his or her intent to revoke.

9. A Patient Advocate may revoke his or her acceptance to the designation at any time and in any manner sufficient to communicate an intent to revoke.

10. A Patient admitted to a health facility or agency has the rights enumerated in MCL 333.20201.

If I am unable to act after reasonable efforts to contact me, I delegate my authority to the Successor Patient Advocate that the Patient has designated, in the order designated. The Successor Patient Advocate is authorized to act until I become available. If I act as Successor, I acknowledge that my authority ends when any higher-ranking patient advocate becomes available.

IN WITNESS WHEREOF, I have executed this *Acceptance of Patient Advocate Designation for Mental Health Treatment* for [CLIENT NAME] this \_\_\_\_ day of \_\_\_\_\_, 2006.

\_\_\_\_\_  
[SPA 1 NAME]

**AUTHORIZATION TO RELEASE PROTECTED HEALTH INFORMATION**

On \_\_\_\_\_, 2006, I signed an *Acceptance of Patient Advocate Designation for Mental Health Treatment* to act as Successor Patient Advocate for [CLIENT NAME].

I therefore authorize any covered entity under HIPAA to disclose protected health information about me for the purpose of determining my capacity to act as Successor Patient Advocate. I hereby voluntarily waive any physician-patient privilege or psychiatrist-patient privilege that may exist in my favor, and I hereby authorize physicians to examine me and disclose my physical or mental condition in order to determine my incapacity or capacity for purposes of acting in the role of agent according to the terms of this document.

This authorization expires upon notice that the Patient Advocate Designation for Mental Health Treatment executed by \_\_\_\_\_ has been revoked or upon notice that I have specifically revoked this authorization. Otherwise, the authorization continues to be valid.

I recognize that I have a legal right to revoke this authorization at any time in writing by sending a notice to that effect to my treating physician or mental health professional.

I recognize that whether or not I sign this authorization has no effect on treatment, payment, enrollment or eligibility for benefits.

I recognize that any information used or disclosed pursuant to this authorization may be subject to redisclosure by the recipient and no longer protected under HIPAA.

Dated: \_\_\_\_\_ [SPA 1 NAME]

## NOTICE TO PATIENT ADVOCATE

The intended purpose of this Patient Advocate Designation for Mental Health Treatment is to address issues related to the Patient's mental health. As the Patient Advocate you are given power under this Patient Advocate Designation to make decisions regarding mental health treatment according with the terms of this Patient Advocate Designation. The Patient directs use your best effort to fulfill your duties under this Patient Advocate Designation consistent the Patient's "Mental Health Care Values History Form." The Patient desires that you have a copy of such form. If you do not have a copy of this form please request one from the Patient's attorney who has been authorized to provide you a copy.

This authority is triggered, if and only if, one physician and one mental health professional determines the Patient is unable to participate in these mental health treatment decisions. The Patient also specifically authorized the release of the Patient's mental health treatment information to you so that you may obtain information from the physician and mental health professional and determine if you are required to serve. If at any time you do not understand this Patient Advocate Designation for Mental Health Treatment or your duties under it, you should ask a lawyer to explain it to you. The Patient authorized you to contact, confer with and hire the Patient's attorney who drafted the Patient Advocate Designation for Mental Health Treatment even if the information communicated between you and the Patient's Attorney would otherwise be confidential or privileged.

By law, you cannot receive compensation for executing your duties as Patient Advocate, from the individual's funds or from any other third parties. You may, however receive reimbursement for actual and necessary expenses paid out of your own funds on behalf of the individual in carrying out your duties and responsibilities as Patient Advocate (e.g., copying fees for mental health treatment records, patient co-pays).

Please also note that although the guidelines and restrictions, as listed in the *Acceptance of Patient Advocate* may not be applicable to your authority or powers granted as a Patient Advocate for Mental Health Treatment, these guidelines and restrictions must be provided to you by law under MCL § 700.5507(4).

Drafted by:  
Patricia E. Kefalas Dudek (P46408)  
BEIER HOWLETT, P.C.  
200 E. Long Lake Road, Suite 110  
Bloomfield Hills, MI 48304-2361  
Telephone: (248) 645-9400

**ACCEPTANCE OF SUCCESSOR PATIENT ADVOCATE DESIGNATION**

I, [SPA 2 NAME], of [SPA 2 CITY], Michigan, acknowledge that I have received a copy of the attached Patient Advocate Designation for Mental Health Treatment and do hereby agree to serve as the Patient Advocate for [CLIENT NAME] (the "Patient") in accordance with both the terms and conditions set forth in the Patient Advocate Designation for Mental Health Treatment and the following guidelines and restrictions:

1. This patient advocate designation is not effective unless the patient is unable to participate in decisions regarding the patient's medical or mental health, as applicable. If this patient advocate designation includes the authority to make an anatomical gift the authority remains exercisable after the patient's death.

2. A Patient Advocate shall not exercise powers concerning the Patient's care, custody, and medical or mental health treatment that the Patient, if the Patient were able to participate in the decision, could not have exercised on his or her own behalf.

3. This Designation cannot be used to make a medical or mental health treatment decision to withhold or withdraw treatment from a Patient who is pregnant that would result in the pregnant Patient's death.

4. A Patient Advocate may decide to withhold or withdraw treatment that would allow the Patient to die only if the Patient has expressed in a clear and convincing manner that the Patient Advocate is authorized to make such a decision and that the Patient acknowledges that such a decision could or would allow the Patient's death.

5. A Patient Advocate shall not receive compensation for the performance of his or her authority, rights, and responsibilities, but a Patient Advocate may be reimbursed for actual and necessary expenses incurred in the performance of his or her authority, rights, and responsibilities.

6. A Patient Advocate shall act in accordance with the standards of care applicable to fiduciaries when acting for the Patient and shall act consistent with the Patient's best interests. The known desires of the Patient expressed or evidenced while the Patient is able to participate in mental health treatment decisions are presumed to be in the Patient's best interests.

7. The Patient may revoke his or her designation at any time and in any manner sufficient to communicate an intent to revoke.

8. The Patient may waive his or her right to revoke this Patient Advocate Designation as to the power to make mental health treatment decisions, and if such a waiver is made, his or her ability to revoke as to certain treatment will be delayed for 30 days after the patient communicates his or her intent to revoke.

9. A Patient Advocate may revoke his or her acceptance to the designation at any time and in any manner sufficient to communicate an intent to revoke.

10. A Patient admitted to a health facility or agency has the rights enumerated in MCL 333.20201.

If I am unable to act after reasonable efforts to contact me, I delegate my authority to the Successor Patient Advocate that the Patient has designated, in the order designated. The Successor Patient Advocate is authorized to act until I become available. If I act as Successor, I acknowledge that my authority ends when any higher-ranking patient advocate becomes available.

IN WITNESS WHEREOF, I have executed this *Acceptance of Patient Advocate Designation for Mental Health Treatment* for [CLIENT NAME] this \_\_\_\_ day of \_\_\_\_\_, 2006.

\_\_\_\_\_  
[SPA 2 NAME]

**AUTHORIZATION TO RELEASE PROTECTED HEALTH INFORMATION**

On \_\_\_\_\_, 2006, I signed an *Acceptance of Patient Advocate Designation for Mental Health Treatment* to act as Successor Patient Advocate for [CLIENT NAME].

I therefore authorize any covered entity under HIPAA to disclose protected health information about me for the purpose of determining my capacity to act as Successor Patient Advocate. I hereby voluntarily waive any physician-patient privilege or psychiatrist-patient privilege that may exist in my favor, and I hereby authorize physicians to examine me and disclose my physical or mental condition in order to determine my incapacity or capacity for purposes of acting in the role of agent according to the terms of this document.

This authorization expires upon notice that the Patient Advocate Designation for Mental Health Treatment executed by \_\_\_\_\_ has been revoked or upon notice that I have specifically revoked this authorization. Otherwise, the authorization continues to be valid.

I recognize that I have a legal right to revoke this authorization at any time in writing by sending a notice to that effect to my treating physician or mental health professional.

I recognize that whether or not I sign this authorization has no effect on treatment, payment, enrollment or eligibility for benefits.

I recognize that any information used or disclosed pursuant to this authorization may be subject to redisclosure by the recipient and no longer protected under HIPAA.

Dated: \_\_\_\_\_

\_\_\_\_\_  
[SPA 2 NAME]

DRAFT

**PATIENT ADVOCATE DESIGNATION FOR MEDICAL AND MENTAL HEALTH**  
**TREATMENT FOR [CLIENT NAME]**

**NOTICE TO PATIENT**

As the “Patient” you are using this Patient Advocate Designation to grant powers to another individual designated as your Patient Advocate. Your Patient Advocate has specific authority to make medical and/or mental health decisions on your behalf. This authority is triggered, if and only if, you are unable to participate in your medical and/or mental health treatment decisions. This authorization is also intended to be a specific release of your medical and/or mental health information to your Patient Advocate so that they can make a determination if they in fact are required to serve. You have the right to take back this designation and revoke it at any time provided that you are of sound mind, unless you have specifically chosen to waive your right to revoke the powers related to mental health treatment. The intended purpose of this Patient Advocate Designation is to address issues including your medical decisions and “end of life” care, and mental health decisions. If at any time you or your Patient Advocate do not understand this Patient Advocate Designation, you should ask your lawyer to explain it. You should complete a Health Care Values History Form and provide a copy to your Patient Advocate.

I, [CLIENT NAME] (the “Patient”), of [CLIENT CITY], Michigan, being of sound mind, full age and under no duress or influence, do hereby make the following Patient Advocate Designation pursuant to MCL 700.5506 and hereby expressly revoke any and all prior Patient Advocate Designations and/or Living Wills which I may have created.

**A. *PATIENT ADVOCATE DESIGNATION FOR MEDICAL TREATMENT***

1. ***Designation of Patient Advocate.*** I hereby designate my [PA RELATION], [PA NAME], of [PA CITY], as my Patient Advocate to exercise powers concerning my care and custody and to make medical treatment decisions for me.

2. ***Designation of Successor Patient Advocate.*** If [PA NAME], the Patient Advocate I have named in Paragraph 1, is unable or unwilling to serve as my Patient Advocate, or becomes incapacitated, resigns or is removed, or is my spouse and an action for separate maintenance, annulment or divorce is filed, I hereby designate my [SPA 1 RELATION], [SPA 1 NAME], of [SPA 1 CITY], Michigan, to act as my Successor Patient Advocate. If [SPA 1 NAME] does not accept, resigns, is incapacitated, dies, is removed, or is otherwise unwilling to act, or is my spouse and an action for separate maintenance, annulment or divorce is filed, I hereby designate my [SPA 2 RELATION], [SPA 2 NAME], of [SPA 2 CITY], Michigan, to act as my Successor Patient Advocate.

If my Patient Advocate is unable to act after a reasonable effort has been made to contact that person, my Successor Patient Advocate is authorized to act until my Patient Advocate becomes available.

**Please refer to page 14 for contact information of my nominated Patient Advocate(s) and Successor Patient Advocate(s).**

3. ***Effective Date and Durability.*** This portion of the document is intended to create a Power of Attorney pursuant to MCL 700.5506 that may be exercised only when I am unable to participate in medical treatment decisions. My attending physician and one other physician or licensed psychologist, after examining me, shall determine whether I am able to participate in medical treatment decisions.

Any determination that I am unable to participate in medical decisions must be in writing, made part of my medical record and reviewed at least annually. If I regain my ability to participate in medical treatment decisions, my designation of a Patient Advocate is suspended but may become effective again if I am subsequently determined to be unable to participate in medical decisions in accordance with the procedure set forth above in this paragraph. This Patient Advocate Designation shall not be affected by my disability and shall continue in effect until my death, with the exception of the authority granted in Section 4(g), or until I revoke it in writing.

4. ***Powers of Patient Advocate for Medical Treatment*** . My Patient Advocate shall be considered my “personal representative” for purposes of the privacy rule issued by the U.S. Department of Health and Human Services and required by the Privacy Rules of the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”). I grant to my Patient Advocate full power and authority to make decisions for me regarding my health care. I intend for my Patient Advocate to have the same authority to exercise my rights of liberty and self-determination that I have while I am competent. In exercising this authority, my Patient Advocate shall follow my expressed wishes, either written or oral, regarding my medical treatment. In making any decision, my Patient Advocate should first try to discuss the proposed decision with me to determine my desires if I am able to communicate in any way. If my Patient Advocate cannot determine the choice I would want based on my written or oral statements, then my Patient Advocate shall choose for me based on what my Patient Advocate believes to be in my best interests.

If this Patient Advocate Designation does not contemplate the particular treatment decision with which my Patient Advocate is faced, then I direct my Patient Advocate to use my Patient Advocate’s best judgment about what my wishes would be, using as a guide the preferences expressed in this Patient Advocate Designation and any other treatment choices I have made, or preferences I have stated while competent that are not reflected in this Patient Advocate Designation.

My Patient Advocate has the power and authority to act in a manner different from that prescribed in this Patient Advocate Designation if my physician advises my Patient Advocate of a medical fact or circumstance, or states a medical opinion, that my Patient Advocate believes would cause me to change my mind about the instructions I have expressed in this Patient

Advocate Designation. Unless specifically limited by this section, my Patient Advocate shall have the power to make each and every judgment necessary for the proper and adequate care and custody of me, including without limitation:

- a) To give or withhold consent to all types of medical care, treatment, surgery, diagnostic procedures, medication, and the use of mechanical or other procedures that affect any bodily function; to revoke, withdraw, modify or change consent to medical treatment, surgery, diagnostic procedures, medication, or the use of mechanical or procedures that affect any bodily function that I or my Patient Advocate may have previously allowed or consented to or which may have been implemented due to emergency conditions;
- b) To summon paramedics or other emergency medical personnel and seek emergency treatment for me, as my Patient Advocate shall deem appropriate;
- c) To request, review and receive any information, verbal or written, regarding my personal affairs or my physical or mental health, including medical and hospital records, and to execute any releases or other documents that may be required to obtain this information, to waive any physician/patient privilege, and to disclose my medical and other personal information to others;
- d) To authorize my admission to any hospital, hospice, convalescent care or nursing home care, residential care, assisted living, or similar facility or service; and to revoke, withdraw, modify or change consent (even against medical advice) to my hospitalization, hospice, convalescent care, nursing home care, residential care or assisted living which I or my Patient Advocate may have previously allowed;
- e) To employ and discharge physicians, psychiatrists, dentists, nurses, therapists, domestic help and other professionals as my Patient Advocate may deem necessary for my physical, mental and emotional well being; and to pay them, or any of them, reasonable compensation;
- f) To consent or refuse consent to the administration of pain-relieving drugs of any type, or other surgical or medical procedures calculated to relieve my pain, including unconventional pain relief therapies which my Patient Advocate believes may be helpful, even though their use may lead to permanent physical damage, addiction or even hasten the moment of (but not intentionally cause) my death;
- g) To make anatomical gifts of my body or of any part thereof which will take effect at my death, as well as the power to donate all or any of my eyes, tissues or organs at the time of my death, to such persons and organizations and in such manner as my Patient Advocate shall deem

appropriate and to execute such papers, and incur such expenses on behalf of my estate as shall be necessary, appropriate, incidental or convenient in connection with such gifts. This power shall also include the power to authorize the release of my medical records and the power to authorize or refuse an autopsy of my body following my death. If I have indicated the manner in which such gifts are to be made, I request that my Patient Advocate carry out my wishes to the extent deemed practical by my Patient Advocate;

- h) To execute any documents titled or purporting to be a “Refusal to Permit Treatment” and “Leaving Hospital Against Medical Advice” or specifically request and concur with the writing of a “No Code” (DO NOT RESUSCITATE) order by the attending or treating physician, as well as any necessary waivers of or releases from liability required by the hospitals or physicians to implement my wishes regarding medical treatment or nontreatment; and
- i) To consult counsel and to take appropriate legal action, if necessary, in my Patient Advocate’s discretion, to enforce and carry out my wishes regarding medical treatment or nontreatment.

5. ***Life Sustaining Treatment: Directive to Withhold or Withdraw Treatment.*** I do not wish to receive or to continue to receive medical treatment (i) that will only postpone the moment of my death from an incurable and terminal condition or (ii) that will prolong an irreversible coma or (iii) if I have irreversible brain damage. For purposes of this Patient Advocate Designation, (i) “terminal condition” means a condition that is reasonably expected to result in my death within six (6) months regardless of the medical treatment that I may receive; and (ii) “irreversible coma” means a permanent loss of consciousness from which there is no reasonable possibility that I may return to a cognitive (capable of understanding) and sapient (capable of reasoning) life, and shall include, but shall not be limited to, a persistent vegetative state; and (iii) “irreversible brain damage” means a permanent condition caused by accident or disease which makes me unable to recognize people and/or understand my surroundings and environment to the point where my quality of life has significantly deteriorated. By “medical treatment,” I mean any diagnostic or therapeutic procedure or test, whether invasive or not, including by way of illustration only, surgery, drugs, renal dialysis, artificial feeding and hydration (including, for example, parenteral feeding, intravenous feeding and endotracheal or nasogastric tube use), cardiopulmonary resuscitation, respirators or ventilators, and any other experimental or non-experimental procedure, therapy or device.

If two (2) licensed and qualified physicians who are familiar with my condition have diagnosed and noted in my medical records that I am unable to give informed consent to medical treatment that is proposed or available for my condition and (i) my condition is terminal as defined above, or (ii) I am in an irreversible coma as defined above, or (iii) I have irreversible brain damage as defined above, then, in such event, I request that the appropriate individuals, health care providers and my Patient Advocate honor the following requests:

- a) Medical treatment (other than artificial feeding and hydration) which will only postpone the moment of my death or prolong my irreversible coma (whether or not such medical treatment is directed toward my terminal condition) should be withheld or, if previously begun, withdrawn.
- b) Any attending physician of mine should write or cause to be issued an effective and enforceable “No Code” or “Do Not Resuscitate” order.
- c) My Patient Advocate should sign on my behalf any and all documents he or she may deem necessary and proper to implement the instructions contained herein, including without limitation, waivers or releases of liability required by any health care provider and consents to “No Code” or “Do Not Resuscitate” orders.
- d) I should be given or administered whatever is appropriate to keep me as comfortable and free of pain as is reasonably possible, including without limitation pain-relieving drugs of any kind, surgical and/or medical procedures calculated to relieve my pain, and unconventional pain-relief therapies which my Patient Advocate believes may be helpful, even though such drugs or procedures may lead to permanent physical damage or addiction, or hasten the moment of my death.
- e) If, in addition to the general circumstances described above, either
  - (i) I am in an “irreversible coma” (as defined above) and such condition has existed for thirty (30) days or more after withdrawal of “life support” devices, such as respirators or ventilators (without limitation) *or*,
  - (ii) it is no longer possible to nourish and hydrate me without severe discomfort because of my “terminal condition” as defined above,

*and* the two physicians described above conclude that

  - (i) nourishment and hydration will not improve my physical condition and
  - (ii) I will not experience pain as a result of the withdrawal of nourishment and hydration,

*then* procedures to provide me with nourishment and hydration (including, without limitation, all forms of intravenous, parenteral and tube feeding and misting) shall be withheld, or, if previously instituted, withdrawn.

In the absence of my ability to give directions regarding the medical treatment or the use of such life-sustaining procedures, it is my intention that this directive be honored by my Patient Advocate, my family, my physician and nurses, and the medical facility as a final expression of my legal right to refuse or withdraw from medical or surgical treatment or care. I fully accept

and acknowledge the consequences, *including my own death*, that may result from authorizing my Patient Advocate to withhold or withdraw treatment that would allow me to die. I understand the full import of this directive, I am emotionally and mentally competent to make this directive and I authorize my Patient Advocate to do any and all things which shall be necessary in order to carry out and effect this directive.

**B. PATIENT ADVOCATE DESIGNATION FOR MENTAL HEALTH TREATMENT**

6. **Designation of Patient Advocate.** I hereby designate [PA NAME], of [PA CITY], Michigan, as my Patient Advocate for Mental Health Treatment to exercise powers concerning my mental health care and to make mental health treatment decisions for me. If the individual nominated as my Patient Advocate does not accept, resigns, is incapacitated, dies, or is otherwise unwilling to act, I appoint [SPA 1 NAME] of [SPA 1 CITY], Michigan, as my Successor Patient Advocate for Mental Health Treatment. If [SPA 1 NAME] does not accept, resigns, is incapacitated, dies, or is otherwise unwilling to act, I appoint [SPA 2 NAME] of [SPA 2 CITY], Michigan, as my Successor Patient Advocate for Mental Health Treatment.

If my Patient Advocate is unable to act after a reasonable effort has been made to contact that person, my Successor Patient Advocate is authorized to act until my Patient Advocate becomes available.

7. **Effective Date and Durability.** This portion of this document is intended to create a Power of Attorney pursuant to MCL 700.5506 that may be exercised only when I am unable to participate in mental health treatment decisions. My physician and a mental health professional, after examining me, shall determine whether I am able to participate in mental health treatment decisions. I wish the mental health professional to be (*select one*):

- \_\_\_\_\_ A physician who is licensed to practice medicine or osteopathic medicine and surgery in Michigan.
- \_\_\_\_\_ A licensed or limited licensed, psychologist practicing in Michigan.
- \_\_\_\_\_ A registered professional nurse licensed to practice in Michigan.
- \_\_\_\_\_ A social worker registered as a certified social worker (until July 1, 2005, but “a licensed master’s social worker”) licensed to practice in Michigan.
- \_\_\_\_\_ A physician’s assistant licensed to practice in Michigan.
- \_\_\_\_\_ A licensed professional counselor under the Public Health Code.

I designate the following individual(s) to make this determination (name and professional):

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Any determination that I am unable to participate in mental health treatment decisions, to do so must be in writing; made part of my mental health treatment records and reviewed at least annually. If I regain my ability to participate in mental health treatment decisions, my designation of a Patient Advocate for mental health treatment is suspended but may become effective again if I am subsequently determined to be unable to participate in medical decisions in accordance with the procedure set forth above. This Patient Advocate Designation for mental health treatment shall not be affected by my disability and shall continue in effect until my death or until I revoke it in writing.

8. ***Powers of Patient Advocate for Mental Health Treatment.*** My Patient Advocate for mental health treatment shall be considered my “Personal Representative” for purposes of the Privacy Rule issued by the U.S. Department of Health and Human Services and required by the Privacy Rules of the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”), and may have full access to my medical and mental health records, including any psychotherapy notes. I grant to my Patient Advocate full power and authority to make decisions for me regarding my mental health treatment and care. I intend for my Patient Advocate to have the same authority to exercise all of my rights as a citizen, including, but not limited to, the right of liberty and self-determination that I have while I am competent, including those specified in the Michigan Mental Health Code, MCL 330.1100 et seq.

In exercising this authority, my Patient Advocate shall follow my expressed wishes, either written or oral, regarding my mental health treatment. In making any decision, my Patient Advocate should first try to discuss the proposed decision with me to determine my desires if I am able to communicate in any way. If my Patient Advocate cannot determine the choice I would want based on my past written or oral statements, or if this Patient Advocate Designation for Mental Health Treatment does not contemplate the particular mental health treatment decision with which my Patient Advocate is faced, then my Patient Advocate shall choose for me based on what my Patient Advocate believes to be in my best interest and is the least restrictive treatment intervention in accordance with my diagnosis and severity of symptoms, and in accordance with Michigan’s Mental Health Code, MCL §330.1100 et seq.

Unless specifically limited by me, either written or oral statements, my Patient Advocate shall have the power to obtain, consent to, and/or refuse treatment on my behalf to ensure I receive proper and adequate mental health care and treatment that is in my best interest and is the least restrictive treatment intervention, including arranging appropriate residential placement, and making payment arrangements to secure the necessary treatment. My Patient Advocate for mental health treatment shall also work with any Representative Payee for any government benefits that I may be entitled to, Conservator, Guardian of my Estate, Agent named under a Durable Power of Attorney, Patient Advocate for medical decisions, or Trustee of a trust established for my benefit, if necessary to fulfill these responsibilities identified herein.

9. ***Specific Grants of Authority.*** My Patient Advocate shall have the following authority regarding my mental health treatment (*Optional*):

a. *Inpatient Psychiatric Hospitalization.* My Patient Advocate (*select one*):

\_\_\_\_\_ shall

\_\_\_\_\_ shall not

have the power to consent to inpatient psychiatric hospitalization and treatment, if it is in my best interest and is the least restrictive treatment, to protect my safety and/or the safety of others, and if in accordance with the civil admission and discharge procedures set forth in Chapter Four of the Michigan Mental Health Code.

However, if I am hospitalized as a formal voluntary patient under an application executed by my Patient Advocate, I retain the right to terminate the hospitalization in accordance with MCL §330.1419.

b. *Forced Administration of Psychiatric Medications.* My Patient Advocate (*select one*):

\_\_\_\_\_ shall

\_\_\_\_\_ shall not

have the power to consent to forced administration of psychiatric medications, if it is in my best interest and is the least restrictive treatment to protect my safety and/or the safety of others.

c. *Electroconvulsive Therapy.* My Patient Advocate (*select one*):

\_\_\_\_\_ shall

\_\_\_\_\_ shall not

have the power to consent to electroconvulsive therapy, or a procedure intended to produce convulsions or coma, in accordance with MCL § 330.1717 of the Michigan Mental Health Code, if it is in my best interest and is the least restrictive treatment to protect my safety and/or the safety of others.

10. ***Waiver of Right to Revoke.*** Regarding the revocation of this portion of my Patient Advocate Designation for mental health treatment (*select one*):

\_\_\_\_\_ I do not waive the right to revoke the powers granted in this Patient Advocate Designation regarding mental health treatment decisions. The powers granted to my Patient Advocate to make mental health treatment decisions will be terminated upon the communication of my intent to revoke.

\_\_\_\_\_ I do waive the right to revoke the powers granted in this Patient Advocate Designation regarding mental health treatment decisions. This waiver does not affect the rights afforded to me to terminate formal voluntary hospitalization under MCL §330.1419. Furthermore, if I communicate at a later time that I wish to revoke this Patient Advocate Designation for mental health treatment while I am deemed unable to participate in decisions regarding mental health treatment, and I am receiving mental health treatment at that time, mental health treatment shall not continue for more than thirty (30) days. I understand that upon termination of the mental health treatment after thirty (30) days, one of the following may occur:

- a. No further treatment will be necessary;
- b. Assisted outpatient treatment is ordered by a court of competent jurisdiction; or,
- c. Involuntary psychiatric hospitalization is ordered by a court of competent jurisdiction under Michigan Mental Health Code, MCL 330.1434 et seq.

11. ***Conflicts with Patient Advocate for Medical Treatment.*** If there is disagreement between my Patient Advocate for mental health treatment and my Patient Advocate for medical care regarding authorization of treatment which affects both my medical status and mental health, instructions from the following shall receive priority (*select one if applicable*):

\_\_\_\_\_ Patient Advocate for Mental Health Treatment, or  
\_\_\_\_\_ Patient Advocate for Medical Care

Furthermore, if a dispute arises as to whether the course of treatment which affects both my medical and mental health status is in my best interest, my Patient Advocate identified above shall obtain the advice from \_\_\_\_\_ to determine the course of treatment. If this conflict is not resolved, then my Patient Advocate for either Mental Health Treatment or Health Care reserves the right to petition the court for instructions.

\*\*\*\*\*

### ***C. ADDITIONAL PROVISIONS***

12. ***Nomination of Guardian.*** If a guardian of my person is necessary, I nominate (*select one*)

\_\_\_\_\_ Patient Advocate for Mental Health Treatment, or  
\_\_\_\_\_ Patient Advocate for Medical Care

to serve as my guardian.

13. ***Binding Effect on Medical and Mental Health Professionals.*** This Patient Advocate Designation shall not be affected by any subsequent disability or incapacity that I may suffer and is intended to be fully binding, without prior court intervention or approval, to the fullest extent provided by MCL 700.5506.

A medical professional who provides medical treatment to me shall comply with my wishes as expressed written or orally, or in this Patient Advocate Designation for Medical and Mental Health Treatment

A mental health professional who provides mental health treatment to a patient shall comply with my wishes as expressed in writing or orally, or in this Patient Advocate Designation for Mental Health Treatment. However, I acknowledge that under MCL §700.5511(4), the mental health professional is not bound to follow that desire if one or more of the following apply:

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

14. ***Third Party Reliance.*** For the purpose of inducing any and all persons connected with the administration of my medical or mental health care, or the implementation of this Patient Advocate Designation, I represent, warrant and agree that if this document is revoked, modified or amended, I and my estate, heirs, successors and assigns will hold any person harmless from any loss suffered or liability incurred as a result of such person acting in good faith upon the instructions of the Patient Advocate prior to the receipt by such person of actual notice of such revocation, modification or amendment, provided such person's actions are not otherwise invalid or unenforceable.

15. ***No Compensation.*** My Patient Advocate shall not be entitled to compensation for services performed under this Patient Advocate Designation, but shall be entitled to reimbursement for actual and necessary expenses incurred as a result of carrying out his/her authority, rights and responsibilities pursuant to this Patient Advocate Designation.

16. ***Separability.*** As required under MCL §700.5513, if a provision of this Patient Advocate Designation conflicts with the Michigan Mental Health Code, the Michigan Mental Health Code shall control. Furthermore, if any provision of this Patient Advocate Designation shall be declared invalid or unenforceable under applicable law, that provision shall not affect the other provisions hereof, and this Patient Advocate Designation shall be construed as if such invalid or unenforceable provision(s) were omitted.

17. ***Binding Effect on Subsequent Disability or Incapacity.*** This Patient Advocate Designation shall not be affected by any subsequent disability or incapacity that I may suffer and is intended to be fully binding, without prior court intervention or approval, to the fullest extent provided by MCL 700.5506. **I direct that this Patient Advocate Designation for Medical and Mental Health treatment be made part of my medical record with my attending physician, and, if applicable, with the facility where I am located. In addition, I direct that this Patient Advocate Designation be made part of my mental health treatment record of the mental health professional providing treatment, the community mental health services program or hospital providing mental health services, and, if applicable, with the facility where I am located.**

**MY ATTORNEY MAY REPRESENT MY PATIENT ADVOCATE**

My attorney who drafted this Patient Advocate Designation may advise and represent my Patient Advocate regarding its use, if my attorney and my Patient Advocate so agree. I understand that my Patient Advocate and I have potentially conflicting interests, because I might disagree with some actions my Patient Advocate might take because of my medical condition. However, to give my Patient Advocate the advantage of my attorney's services and knowledge of my affairs, I am waiving this conflict of interest acknowledging that my Patient Advocate cannot act until, and only when two (2) doctors certify I am unable to participate in medical treatment decisions. I also authorize my attorney in my attorney's discretion to communicate with my Patient Advocate regarding any aspect of my affairs directly related to the document, regardless of whether my attorney represents my Patient Advocate and even if the information communicated would otherwise be confidential or privileged.

**IN WITNESS WHEREOF**, I have signed and delivered this *Patient Advocate Designation* this \_\_\_\_\_ day of \_\_\_\_\_, 2006.

\_\_\_\_\_  
[CLIENT NAME]

**AFFIDAVIT of WITNESSES**

I declare that [CLIENT NAME] (the “Patient”) signed or acknowledged this Patient Advocate Designation in my presence, and that the Patient appears to be of sound mind and under no duress, fraud or undue influence. I am at least eighteen (18) years of age and I am not the person appointed as Patient Advocate by this Patient Advocate Designation, nor am I the Patient’s physician, an employee of the Patient’s life or health insurance provider, or an employee of the health care facility or home for the aged where the Patient resides, or of a community mental health services program or hospital that is providing mental health services to the Patient. Further, I declare that I am not the Patient’s spouse, parent, child, grandchild, sibling, or presumptive heir; and, to the best of my knowledge, I am not entitled to any part of the Patient’s estate under a Will now existing or by operation of law.

WITNESSES:

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name

\_\_\_\_\_  
Name

\_\_\_\_\_  
Address

\_\_\_\_\_  
Address

\_\_\_\_\_

\_\_\_\_\_

**AUTHORIZATION TO RELEASE HEALTH INFORMATION**

On \_\_\_\_\_, 2006, I signed a *Patient Advocate Designation for Medical and Mental Health Treatment* naming [PA NAME] as my Patient Advocate and [SPA 1 NAME] or [SPA 2 NAME] as Successor Patient Advocate. It is important for them to be fully aware of my mental health situation so they can make mental health treatment decisions affairs on my behalf if necessary. For that reason, I sign this authorization.

In accordance with the Privacy Rules of the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”), I authorize \_\_\_\_\_, or any other physician or mental health professional to release to my nominated Patient Advocate and/or Successor Patient Advocate any protected health information for the purpose of determining whether I am unable to participate in medical care treatment decisions.

This authorization expires upon notice that my *Patient Advocate Designation for Medical and Mental Health Treatment* noted above has been revoked, or upon notice that I have specifically revoked this authorization. Otherwise, the authorization continues to be valid.

I recognize that I have a legal right to revoke this authorization to release protected health information at any time in writing by sending a notice to that effect to my treating physicians or mental health professionals.

I recognize that whether or not I sign this authorization has no effect on treatment, payment, enrollment or eligibility for benefits.

I recognize that any information used or disclosed pursuant to this authorization may be subject to redisclosure by the recipient and no longer protected under HIPAA.

Dated: \_\_\_\_\_

\_\_\_\_\_  
[CLIENT NAME]

**CONTACT INFORMATION**

**Patient Advocate(s) & Successor Patient Advocate(s):**

Name of PA: [PA NAME]

Address:

Telephone Number:

Name of Successor PA: [SPA 1 NAME]

Address:

Telephone Number:

Name of Successor PA: [SPA 2 NAME]

Address:

Telephone Number:

**Physician(s) and/or Other Health Care Providers:**

Name:

Title:

Address:

Telephone Number:

Name:

Title:

Address:

Telephone Number:

## NOTICE TO PATIENT ADVOCATE FOR MEDICAL TREATMENT

The intended purpose of this Patient Advocate Designation is to address issues of the Patient's "end of life" care. As the Patient Advocate you are given power under this Patient Advocate Designation to make medical decisions for the Patient's "end of life" care according with the terms of this Patient Advocate Designation. The Patient directs you to use your best effort to fulfill your duties under this Patient Advocate Designation consistent with the Patient's "Health Care Values History Form." The Patient desires that you have a copy of such form. If you do not have a copy of this form please request one from the Patient's attorney who has been authorized to provide you a copy.

This authority is triggered, if and only if, two (2) doctors determine the Patient is unable to participate in these medical decisions. The Patient also specifically authorized the release of the Patient's medical information to you so that you may obtain information from these doctors and determine if you are required to serve. If at any time you do not understand this Patient Advocate Designation or your duties under it, you should ask a lawyer to explain it to you. The Patient authorized you to contact, confer with and hire the Patient's attorney who drafted the Patient Advocate Designation even if the information communicated between you and the Patient's Attorney would otherwise be confidential or privileged.

Please also note that although the guidelines and restrictions, as listed in the *Acceptance of Patient Advocate* may not be applicable to your authority or powers granted as a Patient Advocate for Mental Health Treatment, these guidelines and restrictions must be provided to you by law under MCL § 700.5507(4).

Drafted by:

Patricia E. Kefalas Dudek (P46408)

HAFELI STARAN HALLAHAN CHRIST & DUDEK, P.C.

4190 Telegraph Road, Suite 3000

Bloomfield Hills, MI 48302-2082

Telephone: (248) 731-3080

**ACCEPTANCE OF PATIENT ADVOCATE DESIGNATION FOR MEDICAL TREATMENT**

I, [PA NAME], of [PA CITY], Michigan, acknowledge that I have received a copy of the attached Patient Advocate Designation for Medical and Mental Health Treatment and do hereby agree to serve as the Patient Advocate for [CLIENT NAME] (the "Patient") in accordance with both the terms and conditions set forth in the Patient Advocate Designation for Medical and Mental Health Treatment and the following guidelines and restrictions:

1. This patient advocate designation is not effective unless the patient is unable to participate in decisions regarding the patient's medical or mental health, as applicable. If this patient advocate designation includes the authority to make an anatomical gift the authority remains exercisable after the patient's death.

2. A Patient Advocate shall not exercise powers concerning the Patient's care, custody, and medical or mental health treatment that the Patient, if the Patient were able to participate in the decision, could not have exercised on his or her own behalf.

3. This Designation cannot be used to make a medical or mental health treatment decision to withhold or withdraw treatment from a Patient who is pregnant that would result in the pregnant Patient's death.

4. A Patient Advocate may decide to withhold or withdraw treatment that would allow the Patient to die only if the Patient has expressed in a clear and convincing manner that the Patient Advocate is authorized to make such a decision and that the Patient acknowledges that such a decision could or would allow the Patient's death.

5. A Patient Advocate shall not receive compensation for the performance of his or her authority, rights, and responsibilities, but a Patient Advocate may be reimbursed for actual and necessary expenses incurred in the performance of his or her authority, rights, and responsibilities.

6. A Patient Advocate shall act in accordance with the standards of care applicable to fiduciaries when acting for the Patient and shall act consistent with the Patient's best interests. The known desires of the Patient expressed or evidenced while the Patient is able to participate in medical or mental health treatment decisions are presumed to be in the Patient's best interests.

7. The Patient may revoke his or her designation at any time and in any manner sufficient to communicate an intent to revoke.

8. The Patient may waive his or her right to revoke this Patient Advocate Designation as to the power to make mental health treatment decisions, and if such a waiver is made, his or her ability to revoke as to certain treatment will be delayed for 30 days after the patient communicates his or her intent to revoke.

9. A Patient Advocate may revoke his or her acceptance to the designation at any time and in any manner sufficient to communicate an intent to revoke.

10. A Patient admitted to a health facility or agency has the rights enumerated in MCL 333.20201.

If I am unable to act after reasonable efforts to contact me, I delegate my authority to the Successor Patient Advocate that the Patient has designated, in the order designated. The Successor Patient Advocate is authorized to act until I become available. If I act as Successor, I acknowledge that my authority ends when any higher-ranking patient advocate becomes available.

IN WITNESS WHEREOF, I have executed this *Acceptance of Patient Advocate Designation* for \_\_\_\_\_ this \_\_\_\_ day of \_\_\_\_\_, 2006.

[PA NAME]

**Authorization to Release Protected Health Information**

On \_\_\_\_\_, 2006, I signed an *Acceptance of Patient Advocate Designation for Medical Treatment* to act as Patient Advocate to make medical treatment decisions for [CLIENT NAME].

I therefore authorize any covered entity under HIPAA to disclose protected health information about me for the purpose of determining my capacity to act as Patient Advocate. I hereby voluntarily waive any physician-patient privilege or psychiatrist-patient privilege that may exist in my favor, and I hereby authorize physicians to examine me and disclose my physical or mental condition in order to determine my incapacity or capacity for purposes of acting in the role of agent according to the terms of this document.

This authorization expires upon notice that the *Patient Advocate Designation for Medical and Mental Health Treatment* executed by \_\_\_\_\_ has been revoked or upon notice that I have specifically revoked this authorization. Otherwise, the authorization continues to be valid.

I recognize that I have a legal right to revoke this authorization at any time in writing by sending a notice to that effect to my treating physician or mental health professional.

I recognize that whether or not I sign this authorization has no effect on treatment, payment, enrollment or eligibility for benefits.

I recognize that any information used or disclosed pursuant to this authorization may be subject to redisclosure by the recipient and no longer protected under HIPAA.

Dated: \_\_\_\_\_  
[PA NAME]

## NOTICE TO PATIENT ADVOCATE FOR MEDICAL TREATMENT

The intended purpose of this Patient Advocate Designation is to address issues of the Patient's "end of life" care. As the Patient Advocate you are given power under this Patient Advocate Designation to make medical decisions for the Patient's "end of life" care according with the terms of this Patient Advocate Designation. The Patient directs you to use your best effort to fulfill your duties under this Patient Advocate Designation consistent with the Patient's "Health Care Values History Form." The Patient desires that you have a copy of such form. If you do not have a copy of this form please request one from the Patient's attorney who has been authorized to provide you a copy.

This authority is triggered, if and only if, two (2) doctors determine the Patient is unable to participate in these medical decisions. The Patient also specifically authorized the release of the Patient's medical information to you so that you may obtain information from these doctors and determine if you are required to serve. If at any time you do not understand this Patient Advocate Designation or your duties under it, you should ask a lawyer to explain it to you. The Patient authorized you to contact, confer with and hire the Patient's attorney who drafted the Patient Advocate Designation even if the information communicated between you and the Patient's Attorney would otherwise be confidential or privileged.

Please also note that although the guidelines and restrictions, as listed in the *Acceptance of Patient Advocate* may not be applicable to your authority or powers granted as a Patient Advocate for Mental Health Treatment, these guidelines and restrictions must be provided to you by law under MCL § 700.5507(4).

Drafted by:

Patricia E. Kefalas Dudek (P46408)

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4190 Telegraph Road, Suite 3000

Bloomfield Hills, MI 48302-2082

Telephone: (248) 731-3080

**ACCEPTANCE OF SUCCESSOR PATIENT ADVOCATE DESIGNATION FOR MEDICAL TREATMENT**

I, [SPA 1 NAME], of [SPA 1 CITY], Michigan, acknowledge that I have received a copy of the attached *Patient Advocate Designation for Medical and Mental Health Treatment* and do hereby agree to serve as the Successor Patient Advocate for [CLIENT NAME] (the "Patient") in accordance with both the terms and conditions set forth in the Patient Advocate Designation and the following guidelines and restrictions:

1. This patient advocate designation is not effective unless the patient is unable to participate in decisions regarding the patient's medical or mental health, as applicable. If this patient advocate designation includes the authority to make an anatomical gift the authority remains exercisable after the patient's death.

2. A Patient Advocate shall not exercise powers concerning the Patient's care, custody, and medical or mental health treatment that the Patient, if the Patient were able to participate in the decision, could not have exercised on his or her own behalf.

3. This Designation cannot be used to make a medical or mental health treatment decision to withhold or withdraw treatment from a Patient who is pregnant that would result in the pregnant Patient's death.

4. A Patient Advocate may decide to withhold or withdraw treatment that would allow the Patient to die only if the Patient has expressed in a clear and convincing manner that the Patient Advocate is authorized to make such a decision and that the Patient acknowledges that such a decision could or would allow the Patient's death.

5. A Patient Advocate shall not receive compensation for the performance of his or her authority, rights, and responsibilities, but a Patient Advocate may be reimbursed for actual and necessary expenses incurred in the performance of his or her authority, rights, and responsibilities.

6. A Patient Advocate shall act in accordance with the standards of care applicable to fiduciaries when acting for the Patient and shall act consistent with the Patient's best interests. The known desires of the Patient expressed or evidenced while the Patient is able to participate in medical or mental health treatment decisions are presumed to be in the Patient's best interests.

7. The Patient may revoke his or her designation at any time and in any manner sufficient to communicate an intent to revoke.

8. The Patient may waive his or her right to revoke this Patient Advocate Designation as to the power to make mental health treatment decisions, and if such a waiver is made, his or her ability to revoke as to certain treatment will be delayed for 30 days after the patient communicates his or her intent to revoke.

9. A Patient Advocate may revoke his or her acceptance to the designation at any time and in any manner sufficient to communicate an intent to revoke.

10. A Patient admitted to a health facility or agency has the rights enumerated in MCL 333.20201.

If I am unable to act after reasonable efforts to contact me, I delegate my authority to the Successor Patient Advocate that the Patient has designated, in the order designated. The Successor Patient Advocate is authorized to act until I become available. If I act as Successor, I acknowledge that my authority ends when any higher-ranking patient advocate becomes available.

IN WITNESS WHEREOF, I have executed this *Acceptance of Patient Advocate Designation* for [CLIENT NAME] this \_\_\_\_ day of \_\_\_\_\_, 2006

\_\_\_\_\_  
[SPA 1 NAME]

**AUTHORIZATION TO RELEASE PROTECTED HEALTH INFORMATION**

On \_\_\_\_\_, 2006, I signed an *Acceptance of Patient Advocate Designation for Medical Treatment* to act as Patient Advocate to make medical treatment decisions for [CLIENT NAME].

I therefore authorize any covered entity under the Privacy Rules of the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”) to disclose protected health information about me for the purpose of determining my capacity to act as Patient Advocate. I hereby voluntarily waive any physician-patient privilege or psychiatrist-patient privilege that may exist in my favor, and I hereby authorize physicians to examine me and disclose my physical or mental condition in order to determine my incapacity or capacity for purposes of acting in the role of agent according to the terms of this document.

This authorization expires upon notice that the *Patient Advocate Designation for Medical and Mental Health Treatment* executed by \_\_\_\_\_ has been revoked or upon notice that I have specifically revoked this authorization. Otherwise, the authorization continues to be valid.

I recognize that I have a legal right to revoke this authorization at any time in writing by sending a notice to that effect to my treating physician or mental health professional.

I recognize that whether or not I sign this authorization has no effect on treatment, payment, enrollment or eligibility for benefits.

I recognize that any information used or disclosed pursuant to this authorization may be subject to redisclosure by the recipient and no longer protected under HIPAA.

Dated: \_\_\_\_\_  
[SPA 1 NAME]

**ACCEPTANCE OF SUCCESSOR PATIENT ADVOCATE DESIGNATION FOR MEDICAL  
TREATMENT**

I, [SPA 2 NAME], of [SPA 2 CITY], Michigan, acknowledge that I have received a copy of the attached *Patient Advocate Designation for Medical and Mental Health Treatment* and do hereby agree to serve as the Successor Patient Advocate for [CLIENT NAME] (the "Patient") in accordance with both the terms and conditions set forth in the Patient Advocate Designation and the following guidelines and restrictions:

1. This patient advocate designation is not effective unless the patient is unable to participate in decisions regarding the patient's medical or mental health, as applicable. If this patient advocate designation includes the authority to make an anatomical gift the authority remains exercisable after the patient's death.

2. A Patient Advocate shall not exercise powers concerning the Patient's care, custody, and medical or mental health treatment that the Patient, if the Patient were able to participate in the decision, could not have exercised on his or her own behalf.

3. This Designation cannot be used to make a medical or mental health treatment decision to withhold or withdraw treatment from a Patient who is pregnant that would result in the pregnant Patient's death.

4. A Patient Advocate may decide to withhold or withdraw treatment that would allow the Patient to die only if the Patient has expressed in a clear and convincing manner that the Patient Advocate is authorized to make such a decision and that the Patient acknowledges that such a decision could or would allow the Patient's death.

5. A Patient Advocate shall not receive compensation for the performance of his or her authority, rights, and responsibilities, but a Patient Advocate may be reimbursed for actual and necessary expenses incurred in the performance of his or her authority, rights, and responsibilities.

6. A Patient Advocate shall act in accordance with the standards of care applicable to fiduciaries when acting for the Patient and shall act consistent with the Patient's best interests. The known desires of the Patient expressed or evidenced while the Patient is able to participate in medical or mental health treatment decisions are presumed to be in the Patient's best interests.

7. The Patient may revoke his or her designation at any time and in any manner sufficient to communicate an intent to revoke.

8. The Patient may waive his or her right to revoke this Patient Advocate Designation as to the power to make mental health treatment decisions, and if such a waiver is made, his or her ability to revoke as to certain treatment will be delayed for 30 days after the patient communicates his or her intent to revoke.

9. A Patient Advocate may revoke his or her acceptance to the designation at any time and in any manner sufficient to communicate an intent to revoke.

10. A Patient admitted to a health facility or agency has the rights enumerated in MCL 333.20201.

If I am unable to act after reasonable efforts to contact me, I delegate my authority to the Successor Patient Advocate that the Patient has designated, in the order designated. The Successor Patient Advocate is authorized to act until I become available. If I act as Successor, I acknowledge that my authority ends when any higher-ranking patient advocate becomes available.

IN WITNESS WHEREOF, I have executed this *Acceptance of Patient Advocate Designation* for [CLIENT NAME] this \_\_\_\_ day of \_\_\_\_\_, 2006

\_\_\_\_\_  
[SPA 2 NAME]

**AUTHORIZATION TO RELEASE PROTECTED HEALTH INFORMATION**

On \_\_\_\_\_, 2006, I signed an *Acceptance of Patient Advocate Designation for Medical Treatment* to act as Patient Advocate to make medical treatment decisions for [CLIENT NAME].

I therefore authorize any covered entity under the Privacy Rules of the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”) to disclose protected health information about me for the purpose of determining my capacity to act as Patient Advocate. I hereby voluntarily waive any physician-patient privilege or psychiatrist-patient privilege that may exist in my favor, and I hereby authorize physicians to examine me and disclose my physical or mental condition in order to determine my incapacity or capacity for purposes of acting in the role of agent according to the terms of this document.

This authorization expires upon notice that the *Patient Advocate Designation for Medical and Mental Health Treatment* executed by \_\_\_\_\_ has been revoked or upon notice that I have specifically revoked this authorization. Otherwise, the authorization continues to be valid.

I recognize that I have a legal right to revoke this authorization at any time in writing by sending a notice to that effect to my treating physician or mental health professional.

I recognize that whether or not I sign this authorization has no effect on treatment, payment, enrollment or eligibility for benefits.

I recognize that any information used or disclosed pursuant to this authorization may be subject to redisclosure by the recipient and no longer protected under HIPAA.

Dated: \_\_\_\_\_  
[SPA 2 NAME]

## NOTICE TO PATIENT ADVOCATE FOR MENTAL HEALTH TREATMENT

The intended purpose of this *Patient Advocate Designation* is in part to address issues related to the Patient's mental health. As the Patient Advocate you are given power under this Patient Advocate Designation to make decisions regarding mental health treatment according with the terms of this Patient Advocate Designation. The Patient directs use your best effort to fulfill your duties under this Patient Advocate Designation consistent the Patient's "Values History Form." The Patient desires that you have a copy of such form. If you do not have a copy of this form please request one from the Patient's attorney who has been authorized to provide you a copy.

This authority is triggered, if and only if, one physician and one mental health professional determines the Patient is unable to participate in these mental health treatment decisions. The Patient also specifically authorized the release of the Patient's mental health treatment information to you so that you may obtain information from the physician and mental health professional and determine if you are required to serve. If at any time you do not understand this *Patient Advocate Designation* or your duties under it, you should ask a lawyer to explain it to you. The Patient authorized you to contact, confer with and hire the Patient's attorney who drafted the Patient Advocate Designation for Mental Health Treatment even if the information communicated between you and the Patient's Attorney would otherwise be confidential or privileged.

By law, you cannot receive compensation for executing your duties as Patient Advocate, from the individual's funds or from any other third parties. You may, however receive reimbursement for actual and necessary expenses paid out of your own funds on behalf of the individual in carrying out your duties and responsibilities as Patient Advocate (e.g., copying fees for mental health treatment records, patient co-pays).

Please also note that although the guidelines and restrictions, as listed in the *Acceptance of Patient Advocate* may not be applicable to your authority or powers granted as a Patient Advocate for Mental Health Treatment, these guidelines and restrictions must be provided to you by law under MCL § 700.5507(4).

Drafted by:

Patricia E. Kefalas Dudek (P46408)

HAFELI STARAN HALLAHAN CHRIST & DUDEK, P.C.

4190 Telegraph Road, Suite 3000

Bloomfield Hills, MI 48302-2082

Telephone: (248) 731-3080

**ACCEPTANCE OF PATIENT ADVOCATE DESIGNATION**  
**FOR MENTAL HEALTH TREATMENT**

I, [PA NAME] , of [PA CITY], Michigan, acknowledge that I have received a copy of the attached *Patient Advocate Designation for Medical and Mental Health Treatment* and do hereby agree to serve as the Successor Patient Advocate for [CLIENT NAME] (the "Patient") in accordance with both the terms and conditions set forth in the Patient Advocate Designation and the following guidelines and restrictions:

1. This patient advocate designation is not effective unless the patient is unable to participate in decisions regarding the patient's medical or mental health, as applicable. If this patient advocate designation includes the authority to make an anatomical gift the authority remains exercisable after the patient's death.

2. A Patient Advocate shall not exercise powers concerning the Patient's care, custody, and medical or mental health treatment that the Patient, if the Patient were able to participate in the decision, could not have exercised on his or her own behalf.

3. This Designation cannot be used to make a medical or mental health treatment decision to withhold or withdraw treatment from a Patient who is pregnant that would result in the pregnant Patient's death.

4. A Patient Advocate may decide to withhold or withdraw treatment that would allow the Patient to die only if the Patient has expressed in a clear and convincing manner that the Patient Advocate is authorized to make such a decision and that the Patient acknowledges that such a decision could or would allow the Patient's death.

5. A Patient Advocate shall not receive compensation for the performance of his or her authority, rights, and responsibilities, but a Patient Advocate may be reimbursed for actual and necessary expenses incurred in the performance of his or her authority, rights, and responsibilities.

6. A Patient Advocate shall act in accordance with the standards of care applicable to fiduciaries when acting for the Patient and shall act consistent with the Patient's best interests. The known desires of the Patient expressed or evidenced while the Patient is able to participate in medical or mental health treatment decisions are presumed to be in the Patient's best interests.

7. The Patient may revoke his or her designation at any time and in any manner sufficient to communicate an intent to revoke.

8. The Patient may waive his or her right to revoke this Patient Advocate Designation as to the power to make mental health treatment decisions, and if such a waiver is made, his or her ability to revoke as to certain treatment will be delayed for 30 days after the patient communicates his or her intent to revoke.

9. A Patient Advocate may revoke his or her acceptance to the designation at any time and in any manner sufficient to communicate an intent to revoke.

10. A Patient admitted to a health facility or agency has the rights enumerated in MCL 333.20201.

If I am unable to act after reasonable efforts to contact me, I delegate my authority to the Successor Patient Advocate that the Patient has designated, in the order designated. The Successor Patient Advocate is authorized to act until I become available. If I act as Successor, I acknowledge that my authority ends when any higher-ranking patient advocate becomes available.

IN WITNESS WHEREOF, I have executed this *Acceptance of Patient Advocate Designation* for \_\_\_\_\_ this \_\_\_\_ day of \_\_\_\_\_, 2006.

\_\_\_\_\_  
[PA NAME]

**AUTHORIZATION TO RELEASE PROTECTED HEALTH INFORMATION**

On \_\_\_\_\_, 2006, I signed an *Acceptance of Patient Advocate Designation for Mental Health Treatment* to act as Patient Advocate to make mental health treatment decisions for [CLIENT NAME].

I therefore authorize any covered entity under the Privacy Rules of the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”) to disclose protected health information about me for the purpose of determining my capacity to act as Patient Advocate. I hereby voluntarily waive any physician-patient privilege or psychiatrist-patient privilege that may exist in my favor, and I hereby authorize physicians to examine me and disclose my physical or mental condition in order to determine my incapacity or capacity for purposes of acting in the role of agent according to the terms of this document.

This authorization expires upon notice that the *Patient Advocate Designation for Medical Treatment* executed by \_\_\_\_\_ has been revoked or upon notice that I have specifically revoked this authorization. Otherwise, the authorization continues to be valid.

I recognize that I have a legal right to revoke this authorization at any time in writing by sending a notice to that effect to my treating physician or mental health professional.

I recognize that whether or not I sign this authorization has no effect on treatment, payment, enrollment or eligibility for benefits.

I recognize that any information used or disclosed pursuant to this authorization may be subject to redisclosure by the recipient and no longer protected under HIPAA.

Dated: \_\_\_\_\_  
[PA NAME]

## NOTICE TO PATIENT ADVOCATE FOR MENTAL HEALTH TREATMENT

The intended purpose of this Patient Advocate Designation for Mental Health Treatment is in part to address issues related to the Patient's mental health. As the Patient Advocate you are given power under this Patient Advocate Designation to make decisions regarding mental health treatment according with the terms of this Patient Advocate Designation. The Patient directs use your best effort to fulfill your duties under this Patient Advocate Designation consistent the Patient's "Mental Health Care Values History Form." The Patient desires that you have a copy of such form. If you do not have a copy of this form please request one from the Patient's attorney who has been authorized to provide you a copy.

This authority is triggered, if and only if, one physician and one mental health professional determines the Patient is unable to participate in these mental health treatment decisions. The Patient also specifically authorized the release of the Patient's mental health treatment information to you so that you may obtain information from the physician and mental health professional and determine if you are required to serve. If at any time you do not understand this Patient Advocate Designation for Mental Health Treatment or your duties under it, you should ask a lawyer to explain it to you. The Patient authorized you to contact, confer with and hire the Patient's attorney who drafted the Patient Advocate Designation for Mental Health Treatment even if the information communicated between you and the Patient's Attorney would otherwise be confidential or privileged.

By law, you cannot receive compensation for executing your duties as Patient Advocate, from the individual's funds or from any other third parties. You may, however receive reimbursement for actual and necessary expenses paid out of your own funds on behalf of the individual in carrying out your duties and responsibilities as Patient Advocate (e.g., copying fees for mental health treatment records, patient co-pays).

Please also note that although the guidelines and restrictions, as listed in the *Acceptance of Patient Advocate* may not be applicable to your authority or powers granted as a Patient Advocate for Mental Health Treatment, these guidelines and restrictions must be provided to you by law under MCL § 700.5507(4).

Drafted by:

Patricia E. Kefalas Dudek (P46408)

HAFELI STARAN HALLAHAN CHRIST & DUDEK, P.C.

4190 Telegraph Road, Suite 3000

Bloomfield Hills, MI 48302-2082

Telephone: (248) 731-3080

**ACCEPTANCE OF SUCCESSOR PATIENT ADVOCATE DESIGNATION**

I, [SPA 1 NAME], of [SPA 1 CITY], Michigan, acknowledge that I have received a copy of the attached *Patient Advocate Designation for Medical and Mental Health Treatment* and do hereby agree to serve as the Patient Advocate for [CLIENT NAME] (the "Patient") in accordance with both the terms and conditions set forth in the Patient Advocate Designation for Medical and Mental Health Treatment and the following guidelines and restrictions:

1. This patient advocate designation is not effective unless the patient is unable to participate in decisions regarding the patient's medical or mental health, as applicable. If this patient advocate designation includes the authority to make an anatomical gift the authority remains exercisable after the patient's death.

2. A Patient Advocate shall not exercise powers concerning the Patient's care, custody, and medical or mental health treatment that the Patient, if the Patient were able to participate in the decision, could not have exercised on his or her own behalf.

3. This Designation cannot be used to make a medical or mental health treatment decision to withhold or withdraw treatment from a Patient who is pregnant that would result in the pregnant Patient's death.

4. A Patient Advocate may decide to withhold or withdraw treatment that would allow the Patient to die only if the Patient has expressed in a clear and convincing manner that the Patient Advocate is authorized to make such a decision and that the Patient acknowledges that such a decision could or would allow the Patient's death.

5. A Patient Advocate shall not receive compensation for the performance of his or her authority, rights, and responsibilities, but a Patient Advocate may be reimbursed for actual and necessary expenses incurred in the performance of his or her authority, rights, and responsibilities.

6. A Patient Advocate shall act in accordance with the standards of care applicable to fiduciaries when acting for the Patient and shall act consistent with the Patient's best interests. The known desires of the Patient expressed or evidenced while the Patient is able to participate in medical or mental health treatment decisions are presumed to be in the Patient's best interests.

7. The Patient may revoke his or her designation at any time and in any manner sufficient to communicate an intent to revoke.

8. The Patient may waive his or her right to revoke this Patient Advocate Designation as to the power to make mental health treatment decisions, and if such a waiver is made, his or her ability to revoke as to certain treatment will be delayed for 30 days after the patient communicates his or her intent to revoke.

9. A Patient Advocate may revoke his or her acceptance to the designation at any time and in any manner sufficient to communicate an intent to revoke.

10. A Patient admitted to a health facility or agency has the rights enumerated in MCL 333.20201.

If I am unable to act after reasonable efforts to contact me, I delegate my authority to the Successor Patient Advocate that the Patient has designated, in the order designated. The Successor Patient Advocate is authorized to act until I become available. If I act as Successor, I acknowledge that my authority ends when any higher-ranking patient advocate becomes available.

IN WITNESS WHEREOF, I have executed this *Acceptance of Patient Advocate Designation for Medical and Mental Health Treatment* for [CLIENT NAME] this \_\_\_\_ day of \_\_\_\_\_, 2006.

\_\_\_\_\_  
[SPA 1 NAME]

**AUTHORIZATION TO RELEASE PROTECTED HEALTH INFORMATION**

On \_\_\_\_\_, 2006, I signed an *Acceptance of Patient Advocate Designation for Mental Health Treatment* to act as Successor Patient Advocate to make mental health treatment decisions for [CLIENT NAME].

I therefore authorize any covered entity under the Privacy Rules of the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”) to disclose protected health information about me for the purpose of determining my capacity to act as Patient Advocate. I hereby voluntarily waive any physician-patient privilege or psychiatrist-patient privilege that may exist in my favor, and I hereby authorize physicians to examine me and disclose my physical or mental condition in order to determine my incapacity or capacity for purposes of acting in the role of agent according to the terms of this document.

This authorization expires upon notice that the *Patient Advocate Designation for Medical and Mental Health Treatment* executed by \_\_\_\_\_ has been revoked or upon notice that I have specifically revoked this authorization. Otherwise, the authorization continues to be valid.

I recognize that I have a legal right to revoke this authorization at any time in writing by sending a notice to that effect to my treating physician or mental health professional.

I recognize that whether or not I sign this authorization has no effect on treatment, payment, enrollment or eligibility for benefits.

I recognize that any information used or disclosed pursuant to this authorization may be subject to redisclosure by the recipient and no longer protected under HIPAA.

Dated: \_\_\_\_\_  
[SPA 1 NAME]

## NOTICE TO PATIENT ADVOCATE FOR MENTAL HEALTH TREATMENT

The intended purpose of this Patient Advocate Designation for Mental Health Treatment is in part to address issues related to the Patient's mental health. As the Patient Advocate you are given power under this Patient Advocate Designation to make decisions regarding mental health treatment according with the terms of this Patient Advocate Designation. The Patient directs use your best effort to fulfill your duties under this Patient Advocate Designation consistent the Patient's "Mental Health Care Values History Form." The Patient desires that you have a copy of such form. If you do not have a copy of this form please request one from the Patient's attorney who has been authorized to provide you a copy.

This authority is triggered, if and only if, one physician and one mental health professional determines the Patient is unable to participate in these mental health treatment decisions. The Patient also specifically authorized the release of the Patient's mental health treatment information to you so that you may obtain information from the physician and mental health professional and determine if you are required to serve. If at any time you do not understand this Patient Advocate Designation for Mental Health Treatment or your duties under it, you should ask a lawyer to explain it to you. The Patient authorized you to contact, confer with and hire the Patient's attorney who drafted the Patient Advocate Designation for Mental Health Treatment even if the information communicated between you and the Patient's Attorney would otherwise be confidential or privileged.

By law, you cannot receive compensation for executing your duties as Patient Advocate, from the individual's funds or from any other third parties. You may, however receive reimbursement for actual and necessary expenses paid out of your own funds on behalf of the individual in carrying out your duties and responsibilities as Patient Advocate (e.g., copying fees for mental health treatment records, patient co-pays).

Please also note that although the guidelines and restrictions, as listed in the *Acceptance of Patient Advocate* may not be applicable to your authority or powers granted as a Patient Advocate for Mental Health Treatment, these guidelines and restrictions must be provided to you by law under MCL § 700.5507(4).

Drafted by:

Patricia E. Kefalas Dudek (P46408)

HAFELI STARAN HALLAHAN CHRIST & DUDEK, P.C.

4190 Telegraph Road, Suite 3000

Bloomfield Hills, MI 48302-2082

Telephone: (248) 731-3080

**ACCEPTANCE OF SUCCESSOR PATIENT ADVOCATE DESIGNATION**

I, [SPA 2 NAME], of [SPA 2 CITY], Michigan, acknowledge that I have received a copy of the attached *Patient Advocate Designation for Medical and Mental Health Treatment* and do hereby agree to serve as the Patient Advocate for [CLIENT NAME] (the "Patient") in accordance with both the terms and conditions set forth in the Patient Advocate Designation for Medical and Mental Health Treatment and the following guidelines and restrictions:

1. This patient advocate designation is not effective unless the patient is unable to participate in decisions regarding the patient's medical or mental health, as applicable. If this patient advocate designation includes the authority to make an anatomical gift the authority remains exercisable after the patient's death.

2. A Patient Advocate shall not exercise powers concerning the Patient's care, custody, and medical or mental health treatment that the Patient, if the Patient were able to participate in the decision, could not have exercised on his or her own behalf.

3. This Designation cannot be used to make a medical or mental health treatment decision to withhold or withdraw treatment from a Patient who is pregnant that would result in the pregnant Patient's death.

4. A Patient Advocate may decide to withhold or withdraw treatment that would allow the Patient to die only if the Patient has expressed in a clear and convincing manner that the Patient Advocate is authorized to make such a decision and that the Patient acknowledges that such a decision could or would allow the Patient's death.

5. A Patient Advocate shall not receive compensation for the performance of his or her authority, rights, and responsibilities, but a Patient Advocate may be reimbursed for actual and necessary expenses incurred in the performance of his or her authority, rights, and responsibilities.

6. A Patient Advocate shall act in accordance with the standards of care applicable to fiduciaries when acting for the Patient and shall act consistent with the Patient's best interests. The known desires of the Patient expressed or evidenced while the Patient is able to participate in medical or mental health treatment decisions are presumed to be in the Patient's best interests.

7. The Patient may revoke his or her designation at any time and in any manner sufficient to communicate an intent to revoke.

8. The Patient may waive his or her right to revoke this Patient Advocate Designation as to the power to make mental health treatment decisions, and if such a waiver is made, his or her ability to revoke as to certain treatment will be delayed for 30 days after the patient communicates his or her intent to revoke.

9. A Patient Advocate may revoke his or her acceptance to the designation at any time and in any manner sufficient to communicate an intent to revoke.

10. A Patient admitted to a health facility or agency has the rights enumerated in MCL 333.20201.

If I am unable to act after reasonable efforts to contact me, I delegate my authority to the Successor Patient Advocate that the Patient has designated, in the order designated. The Successor Patient Advocate is authorized to act until I become available. If I act as Successor, I acknowledge that my authority ends when any higher-ranking patient advocate becomes available.

IN WITNESS WHEREOF, I have executed this *Acceptance of Patient Advocate Designation for Medical and Mental Health Treatment* for [CLIENT NAME] this \_\_\_\_ day of \_\_\_\_\_, 2006.

\_\_\_\_\_  
[SPA 2 NAME]

**AUTHORIZATION TO RELEASE PROTECTED HEALTH INFORMATION**

On \_\_\_\_\_, 2006, I signed an *Acceptance of Patient Advocate Designation for Mental Health Treatment* to act as Successor Patient Advocate to make mental health treatment decisions for [CLIENT NAME].

I therefore authorize any covered entity under the Privacy Rules of the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”) to disclose protected health information about me for the purpose of determining my capacity to act as Patient Advocate. I hereby voluntarily waive any physician-patient privilege or psychiatrist-patient privilege that may exist in my favor, and I hereby authorize physicians to examine me and disclose my physical or mental condition in order to determine my incapacity or capacity for purposes of acting in the role of agent according to the terms of this document.

This authorization expires upon notice that the *Patient Advocate Designation for Medical and Mental Health Treatment* executed by \_\_\_\_\_ has been revoked or upon notice that I have specifically revoked this authorization. Otherwise, the authorization continues to be valid.

I recognize that I have a legal right to revoke this authorization at any time in writing by sending a notice to that effect to my treating physician or mental health professional.

I recognize that whether or not I sign this authorization has no effect on treatment, payment, enrollment or eligibility for benefits.

I recognize that any information used or disclosed pursuant to this authorization may be subject to redisclosure by the recipient and no longer protected under HIPAA.

Dated: \_\_\_\_\_  
[SPA 2 NAME]

DRAFT

STATE OF MICHIGAN

IN THE \_\_\_\_\_ COUNTY PROBATE COURT

*In the Matter Of:*

**[PERSON IN NEED OF PROTECTION],**  
An Alleged Person in Need of Protection

Case No.  
Hon.

Patricia E. Kefalas Dudek (P46408)  
*Attorney for Petitioner*  
BEIER HOWLETT, P.C.  
200 E. Long Lake Road, Suite 110  
Bloomfield Hills, MI 48304  
(248) 645-9400

**PETITION FOR ORDER TO SEAL RECORDS**

PETITIONERS, **[PETITIONER/CLIENT]**, through their attorney, BEIER HOWLETT, P.C., and for their *Petition for an Order to Seal Records*, represent unto this Honorable Court as follows:

1. **[PERSON IN NEED OF PROTECTION]** is a \_\_\_\_ year old man, born on \_\_\_\_\_.
2. **[PERSON IN NEED OF PROTECTION]** currently resides in \_\_\_\_\_, Michigan.
3. **[PERSON IN NEED OF PROTECTION]** has one adult son, \_\_\_\_\_, Petitioner, and one adult daughter, \_\_\_\_\_.
4. **[PERSON IN NEED OF PROTECTION]** is the sole stockholder, director and officer of \_\_\_\_\_ Company, Inc., the general partner of the various companies under the umbrella of \_\_\_\_\_, and retains exclusive management and control of all these businesses within this entity. On information and belief, one hundred (100%) percent of the stocks of \_\_\_\_\_ Company, Inc. is owned by **[PERSON IN NEED OF PROTECTION]**'s Revocable Trust. **[PERSON IN NEED OF PROTECTION]**'s interests in the businesses are part of the Trust, which he manages as Trustee of his Trust.
5. There are over two hundred individuals employed by \_\_\_\_\_.
6. **[PERSON IN NEED OF PROTECTION]** is a prominent and a respected business person in the community.

7. In 1999, [PERSON IN NEED OF PROTECTION] began exhibiting signs of decline in his cognitive functioning. [PERSON IN NEED OF PROTECTION] has been evaluated and treated with various medications to address the symptoms of Alzheimer's Dementia ever since.

8. Since his decline, [PERSON IN NEED OF PROTECTION] has engaged in questionable transactions related to his company. He is no longer able to make decisions in the best interest of his company, or for himself. See *Affidavit of [NAME OF WITNESS]*, attached as *Exhibit \_\_\_\_*.

9. Petitions for the appointment of guardian and conservator, have been filed concurrently with this Court.

10. \_\_\_\_\_ Bank, who oversees all of the company's transactions, has now refused to approve any new lines of credit until the resolution of concerns related to [PERSON IN NEED OF PROTECTION]'s cognitive capacities.

11. MCL § 700.5401 states in pertinent part:

*“(3) The court may...make another protective order in relation to an individual's estate and affairs if the court determines both of the following:*

*(a) The individual is unable to manage property and business affairs effectively for reasons such as mental illness, [and] mental deficiency...”*

*(b) The individual has property that will be wasted or dissipated unless proper management is provided...”*

12. MCR 8.119(F) states:

*“(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.*

13. Petitioners request that this Court seal the records related to this action, including omission of information regarding the nature of these proceedings in this Court's computer database, in order to protect the interests of [PERSON IN NEED OF PROTECTION] and his company and its business employees.

14. The company and [PERSON IN NEED OF PROTECTION]'s interests are subject to irreparable injury, loss and damage should the employees discover that there is no one who is heading the operations other than [PERSON IN NEED OF PROTECTION] who's mental capacity is in serious question.

15. The company and [PERSON IN NEED OF PROTECTION]'s interests are also subject to irreparable injury, loss and damage should persons engaging in business transactions with [PERSON IN NEED OF PROTECTION] on behalf of the company discover that [PERSON IN NEED OF PROTECTION]'s mental capacity is in serious question. Discovery of this information would open the door for abuse and exploitation, and make it impossible for the business to resolve disputes and negotiate pending necessary transactions.

16. There is no less restrictive means to protect the reputation and interests of [PERSON IN NEED OF PROTECTION] and his company.

17. The interested persons are as follows: [INSERT NAME AND ADDRESSES OF ALL INTERESTED PERSONS]

THEREFORE, Petitioner requests this Court to issue an Order to:

- A. Seal the entirety of this record related to this matter.
- B. Remove from this Court's computer database the exact nature of these proceedings.
- C. Grant any other relief this Court deems equitable and appropriate under the circumstances.

**I DECLARE THAT THE ABOVE STATEMENTS ARE TRUE TO THE BEST OF MY INFORMATION, KNOWLEDGE AND BELIEF.**

**PETITIONER:**

DATED: \_\_\_\_\_, 2005

\_\_\_\_\_  
[NAME OF PETITIONER]

*By their Counsel:*

**BEIER HOWLETT, P.C.**

By:

\_\_\_\_\_  
Patricia E. Kefalas Dudek (P46408)  
*Attorney for Petitioner*  
200 E. Long Lake Road, Suite 110  
Bloomfield Hills, MI 48304-2361  
(248) 645-9400

## Meaning of Homeownership for Individuals With Developmental Disabilities: A Qualitative Study

David Hagner, Judith Snow, and Jay Klein

### Abstract

In-person semi-structured interviews were conducted with 7 homeowners selected by 6 state homeownership programs as representing good examples of homeownership by individuals with developmental disabilities. Recurring themes were found in the choice of a home, advantages and disadvantages of homeownership, handling problems, community relationships, finances, supports, future plans, and homeownership 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. A variety of external factors, including some undue control of the process by service providers and family members, appeared to add to the difficulties homeowners faced. Implications for improvements in homeownership assistance programs are discussed.

Homeownership has long been regarded as a central component of the "American dream." The advantages that have been associated with owning one's own home include (a) a greater degree of choice and control (Galbraith, 2001; O'Brien, 1994), (b) more housing and neighborhood stability (Everson & Wilson, 2000), (c) an improved sense of community attachment (Cuba & Hummon, 1993; Mesch & Manor, 1998), (d) greater economic security and opportunity to accumulate equity (Page-Adams & Sherraden, 1997; Wilson & Everson, 2000), (e) enhanced community status (Everson & Wilson, 2000), and (f) increased social and community involvement (Howe, Horner, & Newton, 1998; Rohe & Basalo, 1997).

Control over one's own residence has been increasingly recognized as an important consideration for advancing the choice and control of adults with developmental disabilities over their own lives (McCarthy, 2000). Restricted opportunities for individuals with disabilities to make decisions or to exercise choice in matters that directly affect daily life (Kishi, Teelucksingh, Zollers, Park-Lee, & Meyer, 1998) reflect, in part, the restrictive environments in which people have historically been placed (Duvdevany, Ben-Zur, & Ambar, 2002). Greater

control over one's living environment is recognized as a critical feature of self-determination for adults with developmental disabilities (Stancliffe, Abery, & Smith, 2000) and has been one of the motivating forces behind the movements towards self-directed funding (Turnbull & Turnbull, 2001) and personalized supports (Blumberg, Ferguson, & Ferguson, 2000).

Several initiatives have demonstrated the viability of homeownership for individuals with developmental disabilities. One of the most notable example is that an estimated 900 individuals were assisted in purchasing their own homes through state coalitions affiliated with the National Home of Your Own Alliance between 1994 and 1998 (Klein & Nelson, 2000). Feinstein, Levine, Lemanowicz, Klein, and Hagner (in press) conducted a study of 129 successful, unsuccessful, and pending homeowners in 9 of these states and investigated the impact of homeownership on quality of life in the areas of choice, control, inclusion, independence, relationships, and participation in the local economy. Homeowners reported significantly higher levels of choice, control, and participation in the local economy than did nonhomeowners, but they were not significantly different in their levels of community activity and social relationships.

To obtain a complete picture of the impact of homeownership on quality of life, however, it is also important to look in detail at the subjective meanings of homeownership from the point of view of homeowners with developmental disabilities. *Home* has a variety of personal meanings for each person (Cuba & Hummon, 1993), embedded in everyday experiences and surroundings (Feldman, 1996). Anison (2000) noted that although the word *home* has been used to describe a variety of residential options for individuals with developmental disabilities, these options have not necessarily been experienced by the residents as homes, and many have been anything but homelike.

O'Brien (1994) viewed homeownership as having three dimensions: (a) individuals experience a sense of place, inhabiting the residence in a comfortable and personalized way; (b) individuals control the home and the support they need to live there; and (c) individuals feel secure and stable in their residence. He cautioned against two particular tendencies to be avoided in the pursuit of homeownership. The first is a tendency to "dump" people into substandard dwellings or neighborhoods, and the second is a tendency to continue traditional agency-controlled practices while merely relabeling residences as consumer-owned homes.

In anecdotal reports Blumberg et al., (2000), Hepp and Soper (2000), and Stocke (1998) have described the experiences of individual homeowners in positive terms, but there has been little systematic investigation of how such individuals feel about pursuing homeownership or their experiences in purchasing and owning their homes. Using a focus group methodology, Everson and Wilson (2000) explored the perspectives of participants in one state homeownership program. They found that homeowners with disabilities were highly satisfied with their homes, their neighborhoods, and their status as homeowners. The time and cost involved in home maintenance and repairs was a disadvantage they perceived as a necessary part of an overall positive arrangement.

Our purpose in the present study was to explore the meaning of homeownership for successful homeowners across several states through in-depth interviews and visits to individuals in their homes. Conducting interviews in individuals' own "turf" allowed opportunities for interviewees to use tours of their homes and yards and show items within their homes that allowed them to expand upon and illustrate their stories, as well as opportunities for

interviewers to observe a small sample of interactions between homeowners and housemates, support providers, and community members in their natural settings.

## Method

The first two authors interviewed 7 homeowners in 6 states; 1 interview was with a couple who owned their home and were interviewed together. All homeowners were individuals with developmental disabilities who had acquired their homes with assistance from the Home of Your Own project in their state. A purposeful sampling process (LeCompte & Preissle, 1993) was used to identify participants. Homeownership assistance project offices in states that were geographically dispersed within the United States were contacted: Arkansas, Connecticut, Missouri, Pennsylvania, Texas, and New Hampshire. Two of these were affiliated with state Independent Living Centers and 1, with a state Developmental Disabilities Council; 1 was a state Housing Finance Authority and 2, independent organizations. Coordinators of each program were asked for assistance in identifying an individual they considered to be a good example of homeownership success who was interested in a visit and interview. Each individual nominated was contacted and consented to the site visit.

The purposeful identification of positive examples is a sampling strategy within the tradition of what Bogdan and Taylor (1990) called "optimistic research." Selecting particularly positive examples helps bring the details of a topic of interest, such as the experience of homeownership, into sharper focus and helps sort out a wealth of information useful for guiding service providers and advocates in their efforts to replicate or extend what has been accomplished in these successful situations.

The interviewees included 3 women and 4 men, ranging in age from 32 to 61 years, with an average age of 45. The length of time of homeownership varied from 10 months to 7 years. Demographic and home information for the interviewees is summarized in Table 1.

Interviews were conducted in-person in the interviewee's home, with the exception of one interview that took place in two parts, first at a restaurant near the individual's job over dinner, followed by a visit to the home. The first 2 interviews were conducted by both interviewers together. This al-

## Meaning of homeownership

Table 1 Homeowner Interviewees

Name	Age	Home type	Length of ownership <sup>a</sup>	Personal support	Employment
Anthony	38	Single-family	5	On-call staff	Full-time paid
Jordan & Kathleen	61, 53	Condo	7	Scheduled personal assistance	Part-time volunteer
Roberta	44	Single-family	1	Live-in personal assistance, position currently vacant	Unemployed
Charles	43	Single-family	3	Shift staff	Part-time self employment
Samuel	32	Single-family	2	Live-in family member; scheduled personal assistance	Full time paid
Marilyn	42	Co-op	10	Live-in personal assistant	2 part-time paid jobs

<sup>a</sup>In years except for Marilyn, who had lived in her condo for 10 months.

lowed the interviewers to meet afterwards and discuss and compare their observations to ensure that their understanding of responses and overall impressions of the visit were consistent. The remaining interviews were conducted by one interviewer.

A list of semi-structured questions was developed for the interviews, based on our review of homeownership literature. Topics included the choice of a home, advantages and disadvantages of ownership, dealing with problems, community relationships, finances, supports, future plans, and homeownership advice. An informal, conversational style was maintained, and interviewees were encouraged to include any additional topics.

The interviews were audiotaped and transcribed, with the exception of the restaurant portion of one interview, where background noise prevented recording, so the interview was recorded by means of written notes. Site visits also included a tour of each homeowner's house and yard, and observational impressions from these tours were included as fieldnotes and added to the interview transcriptions.

Support persons were present for 4 of the interviews: a homeownership program manager, a service coordinator, a mother/housemate, and a live-in support provider. In 2 of these situations, the support person added comments when asked by the homeowner or provided supplemental clarifying information following the individual's answer. In 2 other interviews, the support person volunteered to

answer several of the questions posed to the individual, with the apparent acquiescence of the individual.

The transcribed data were content-analyzed using inductive techniques (Bogdan & Biklen, 1992). The full set of notes and transcriptions was reviewed by the 2 interviewers and a third investigator, who each developed an independent list of recurring themes for each main topic across all interviews. Discussion among the three investigators refined these lists into a single set of study findings.

## Findings

All 7 individuals were homeowners, with some variations on the type of ownership. Anthony, Roberta, Charles, and Samuel owned private homes, Jordan and Kathleen owned a condominium together, and Marilyn's home was owned by a housing cooperative of which she was a member. Findings about the meaning of homeownership for these individuals are presented in relation to each of the major interview topic areas.

### *Choosing and Purchasing a Home*

For each interviewee, their major reason for pursuing homeownership was an interest in having more choice and control in their lives. This interest was not an abstraction; it expressed itself in relation to particular life areas of primary importance for each individual.

Charles, for example, was primarily interested in living in a place where he was not dependent on a landlord for making repairs. In the past he had experienced delays, and when he saw a problem, he wanted it taken care of quickly. Stephen and Marilyn each primarily wanted the long-term security in their residence that ownership provided. Roberta wanted a quiet location with room for a garden. Other personal interests and needs that informed participants' interest in homeownership and their selection of a particular home included (a) close proximity to work or volunteering opportunities, (b) more space, (c) a safer neighborhood, and (d) the opportunity for pet ownership.

All of the participants reported that buying their home had been a lengthy and arduous process. As Charles noted:

For me, it was pretty hard to go through the process. The waiting. There were times you'd get impatient, and you'd just have to put up with it. The waiting. Because they had to check your credit, see if they accepted you, and all that.

Homeownership programs and services were perceived as helpful in assisting the interviewees to navigate through the process of purchasing their homes. For example, 2 interviewees mentioned that they had benefited from homeownership preparation classes sponsored by their state program.

During visits to their homes, all of the homeowners pointed out specific features that reflected their individual preferences and lifestyles. For example, 3 interviewees had dogs, and 1 had a pair of tropical birds. Anthony was proud of the new barbecue grill on his back deck and explained that he enjoyed cooking outdoors whenever he could. Marilyn had converted one room of her home to serve as a craft room, with several projects in various stages of completion.

All but one homeowner reported that they had had to make compromises in relation to their initial expectations and that some external factors influenced the final choice of a home. For Anthony, Jordan, and Kathleen, and Charles, the state homeownership program had predetermined the home location to a large extent by selecting the neighborhood for project activities or by actually building the homes on a particular street. For Stephen, his mother, who also lived in the home, had played a major role in selecting the home. Roberta's live-in caregiver urged her to consider a home with enough property for a large garden, something of interest to the caregiver, and this restricted the selection of homes available to Roberta.

### *Advantages and Disadvantages of Ownership*

All of the interviewees preferred homeownership to their previous living arrangement. The feeling of independence and self-determination that came from having a home far outweighed any disadvantages. Anthony expressed this point as follows: "With my own place, nobody can tell me what to do. I can stay up late if I want. I'm responsible to take care of me, and nobody else." Stephen elaborated on how homeownership allowed full expression to his convictions about personal responsibility.

I like having my own place and having the say about who comes in. And I like having responsibility for my own decisions. I feel like it's my responsibility to make decisions for the house. There are people out there who are going to tell you "This is the right thing to do," but you are the one who has to decide for yourself.

Personal control of one's living space was a particularly important aspect of homeownership. For example, Jordan explained how he and Kathleen had redesigned their bathroom exactly the way they wanted it. A related aspect of ownership was the feeling of enhanced equality and social status afforded the participants. Anthony related a conversation he had had with his sister and his cousin shortly after moving in to his home: "My sister and my cousin were surprised when they first found out I had a home. They asked me 'How can you afford it?' I asked them 'Well, you've got a house too. How do you afford it?'"

Ironically, the biggest advantage of homeownership was also its biggest disadvantage. As Jordan stated, "It is a big responsibility. You have to take care of everything yourself. It's not like you have someone else who will take care of it, like when you rent."

Careful budgeting and responsible bill-paying were ongoing issues, and difficulties staying within a strict budget were mentioned in every interview. As Anthony put it, "All my money seems to go right down a hole." A related disadvantage was the ongoing need to attend to repair and upkeep of the home. This responsibility could pose substantial difficulties. When the interviewer rang the front doorbell, Jordan called from inside to ask the interviewer to enter. He explained that his electric door opener was broken. While waiting for repairs to be made to the front door, he and Kathleen, who both had mobility impairments, used the back door to enter and leave their home.

Stephen had difficulty with accessibility within his two-story home. In order to take a bath or show-

er, he had to use a stair glide to go up to the second floor, and he was afraid that the stair glide in his home was not completely safe. A new stair glide was on order.

Anthony felt that his house was too small to accommodate him and his housemate Joe. Joe had moved into the second bedroom of the home because the homeownership program office had told Anthony that he needed the financial contribution that this second individual would provide. Anthony felt that Joe had taken over the most convenient kitchen cupboards with his own kitchen supplies, and he disliked the fact that Joe had had a pool table brought into the living room, taking up pretty much the entire room. Joe had told Anthony that he had gotten a good deal on it and had no other place to put it, so Anthony felt that he had to put up with it.

### *Handling Problems*

When problems occurred with the home, homeowners received assistance from agencies, providers of generic community services, and unpaid friends and family members. The interviewees made use of the typical array of repair and upkeep services available in any community either directly (e.g., by looking up the number of a plumber in the phone book and calling) or indirectly (e.g., by calling a support staff person or a family member who would call a plumber).

Most homeowners described specific steps they had taken to obtain contact information about the services they were likely to need. Stephen, for example, explained that if his mother was not available, he would call his sister, and she would advise him on what to do.

Interviewees felt that they were adequately coping with problems, with some notable exceptions. The interviewees who relied on Medicaid to pay for accommodations they needed to live in the home (e.g., the stair glide and door opener) complained that it was time-consuming and complicated to get Medicaid-funded items repaired or replaced when they malfunctioned. Roberta experienced her support system as unstable, in that she needed more support than her informal network of friends could provide, and she was having difficulty arranging for a live-in support person to replace the caregiver who had left.

### *Community Relationships*

Interviewees interacted frequently with family, friends, neighbors, service providers, and other

community members. Stephen, for example, had a list of people he referred to as his "circle of support" whom he could call when he needed something: "I can call them up today and say 'Let's go shopping,' and they'll make arrangements for one of them to come out and help me out."

Some direct evidence of such community interactions occurred during the interviews. A driver came to the door to transport Kathleen to an appointment, and a pest control service technician called at the door during the interview with Charles. In both cases it was clear that the homeowner had ongoing friendly relationships with these individuals.

All of the interviewees maintained close relationships with people who had helped them select and purchase their home and who had a significant impact on their life. Most interviewees had also gotten to know and like several of their neighbors, and they related specific occasions when their neighbors had been sources of support.

Despite these contacts, a degree of loneliness was a theme in three interviews. Two interviewees mentioned a wish to have a close intimate relationship with another individual, with whom they could share their home and their life. However, neither had a plan to achieve their dream. Charles, who had had a roommate who had not worked out, was asked whether he liked it better living alone or would perhaps like to try living with someone again. He simply sighed.

Two interviewees had full-time jobs, and 2 others had consistent part-time jobs or volunteer responsibilities. Roberta was currently unable to work at her job because of a lack of adequate personal care, and Charles operated his own vending machine business as a form of part-time self-employment. Charles reported that "it has been a lot of trouble," however, and that he was hoping to sell the business.

### *Finances*

All interviewees felt that ownership made better financial sense than renting. The primary advantage was that payments for mortgages and taxes increased more slowly than rental costs. Although managing finances was difficult and stressful at times, Jordan and Kathleen handled their own money management, and the remaining interviewees received formal or informal assistance with their finances.

Samuel used some of his personal support fund-

ing to pay an accountant to help with his finances. The accountant visited every few weeks to review Samuel's bills with him. For major financial decisions, Samuel called his "circle of support" to his home for a meeting.

For several other individuals, financial planning was dealt with by removing it from the homeowner's control. Charles had had significant debt problems, and these had been resolved by naming Charles's aunt as his representative payee for his Supplemental Security Income and providing her with addresses for all of his bills. For Marilyn, the developmental service agency supporting her was her representative payee and handled most of her bills. Both of these interviewees were satisfied with the arrangement and believed that there was no alternative.

### Supports

Roberta and Marilyn had live-in assistants, but Roberta reported that her assistant had recently left, and she was searching for a replacement. Charles had continual staff assistance on a rotating shift basis, arranged by the residential service organization that had assisted him in obtaining his home. The remaining interviewees had access to part-time or on-call support, and Samuel's mother lived in his home.

Relationships with support persons were reported to be satisfactory, with one exception. Charles reported having a problem in the past with a direct support staff person offering to contribute towards the cost of a pay-per-view wrestling TV show and then renegeing.

Samuel's mother and Marilyn's live-in support provider were present during and participated actively in the interviews. It was sometimes difficult to separate the views of the homeowner from the views of these support persons. An example illustrates this difficulty. Samuel's "bedroom" was not really a room but an alcove on the first floor separated from the living room by a curtain. When Samuel was asked whether that was his bedroom, his mother, who occupied the real bedroom, answered for Samuel: "That's the way he wants it. He makes the decisions, and he tells me what he wants." Later, however, in the interview, when asked whether he would like to have his own bedroom, Samuel replied "Well, yes." Samuel did not want the existing bedroom because it was upstairs, and he was afraid the stair glide was unsafe for him to use, so he acquiesced in the alcove arrangement.

### Future Plans

Although this topic was not among the list of interview questions, all of the interviewees volunteered information about plans underway for changes in their homes. This future orientation, and the obvious delight participants showed in making, revising, discussing, and implementing long-term plans for the home and yard, was central to the meaning of ownership for them. Three homeowners, for example, had plans to add or enclose a deck outside the back of the home, and one had plans for doing some kitchen redesign and landscaping work to the yard.

Two interviewees would ideally have liked to move to a different home. Roberta felt that her house and yard were too big and isolated, and Anthony believed that his home was too small and in a part of town requiring too many bus transfers for him to access his job and affordable shopping. Neither homeowner appeared to have access to adequate support to investigate other housing options. For example, Anthony believed that because he had signed a 15-year mortgage, he was required to live in his home for 15 years. Feeling certain that there was no solution to his problem, he had not brought it to anyone's attention.

### Homeownership Advice

Two homeowners had no specific advice for others considering homeownership. The remaining interviewees articulated several lessons they had learned and wished to communicate to new homeowners. Their advice is summarized as follows:

- Make sure you look around. Is this what you are looking for? Put as much time into it as you need to, to make the right decision.
- Make sure you have enough money and that your finances are straight.
- Take advantage of homeownership classes.
- Read everything before you sign it, especially the fine print. People might try to sneak something in there. There are pitfalls to not being careful, and it's a big pit.
- Always ask yourself "Is this right for me?" Get advice, but then make your own decision.

Jordan warned that despite following all of the advice available, a homeowner should expect that there will still be unanticipated problems. "No matter how much you prepare, you will never know everything. There were times when we just had to wing it."

## Discussion

Homeownership for people with developmental disabilities is still in its early stages, and the selected sample of 7 homeowners from 6 states is very small. However, several tentative insights can be drawn from these data regarding the meaning of homeownership and the process of supporting homeownership for individuals with developmental disabilities.

Selecting and purchasing a home was experienced as a long and arduous process, but worth the effort. Interviewees reported having multiple and satisfying connections with a network of neighbors, family, and other community members. Most important, though, was the sense of freedom and social status that homeownership clearly provided, particularly the opportunity for the homeowners interviewed to express their individuality and make long-term plans in a way that they had not previously experienced.

Money management was difficult for several interviewees; some of the responses to these financial difficulties by residential program staff and families seemed to be "overkill," in that they removed responsibility and control from individuals who clearly wanted opportunities to learn responsibility.

A variety of supports were evident across all 7 participants, but there was also evidence of misalignment between the support needed by and the support provided to several individuals. Roberta, a woman who was blind and quadriplegic, had difficulty supervising acres of yard work. Anthony had to put up with a pool table dominating his living room and kitchen cupboards taken over by an uninvited housemate, and Samuel used a curtained-off living room alcove as his bedroom and was frightened to go upstairs to take a bath. Jordan and Kathleen were blocked from entering or leaving their front door for months.

These problems resulted in large part from events that were unforeseen at the time of the initial purchase of and adjustment to the home. Thus, the issue seemed to be a deficiency in long-term sustainability and flexibility of support as unanticipated problems unfolded. For example, Anthony had been assisted to buy a home in a neighborhood with no affordable shopping and far from his work. His mortgage costs were contained, but his transportation and grocery costs were far higher than expected. The "solution" presented to Anthony was to accept an annoying housemate to share some of the costs. Samuel was afraid to go upstairs because his stair glide, while ap-

parently not mechanically unsafe, felt unstable to him when he used it. Research into assistive technology use has shown that technology must not only "work" in a technical sense, but must feel comfortable to the user (Riemer-Ross, 1999). These interviewees reacted to their difficulties with resignation, putting up with inconveniences in a way we sometimes refer to as being *philosophical*. Part of the explanation may be that many of the homeowners interviewed relied on the same people to support them in solving problems who also helped them make sense of the meaning of events and circumstances. Problems that were not in fact solved tended to be viewed as unsolvable.

Many of the difficulties experienced by these homeowners are those typical for low-income homeowners without disabilities. Other difficulties apply not only to homeownership itself, but to the receipt of long-term individualized disability supports. For example, research has suggested that individuals with developmental disabilities can face difficulties in forming close friendships (Pottie & Sumah, 2004) and problems with the quality of services funded by Medicaid have been widely documented (e.g., Foster, Brown, Phillips, Schue, & Carlson, 2003). However, the need for effective supports seems to be especially critical in situations where an individual has become responsible for his or her living environment. Blumberg et al. (2000) found that it was the process of arranging supports for homeownership that drove their efforts to redesign the way services were organized and delivered, to ensure sufficient responsiveness and individualization. As Turnbull and Turnbull noted (2001), any gaps between decisions that need to be made and acted upon and an individual's cognitive ability must be filled by trusted allies. Formal and informal supports must be of sufficient strength and balance to ensure that support network members do not perceive efforts to improve the quality of life of an individual with a developmental disability as negatively impacting their own quality of life.

Several limitations should be kept in mind relating to the small sample used in this study. First, the length of homeownership varied widely across interviewees, and because the experience of homeownership may change over time, it is difficult to assess whether any differences in perspective across interviewees were a function of the length of time individuals had owned their homes. In addition, the respondents were all conversationally competent, and it is possible that their experiences might be different from those of homeowners with more sig-

nificant communication limitations. Finally, program managers identifying what they believed as especially successful examples may have differed in the extent of their involvement with and personal knowledge of the homeowners served by their program and, thus, in their ability to identify who was and was not particularly successful.

## Conclusion

On O'Brien's (1994) three dimensions of homeownership—a sense of place, control over the residence and personal supports, and security and stability—the reports from homeowners we visited and talked with at length were mixed. All of the homes were comfortable, well-furnished, in good repair, and in safe and welcoming neighborhoods. Opportunities for individual expression, such as by raising tropical birds or building a back deck, were evident. Control was compromised in a number of ways, however. Anthony did not want a pool table in his living room or a housemate; and sleeping in an alcove with a curtain instead of in a bedroom was not Samuel's preference. Roberta's difficulties obtaining live-in assistance to help care for her home and grounds were a source of constant worry in her life.

Although the participants in this study were unanimous in preferring homeownership to any other residential arrangement, the difficulties they reported were more serious than has been reported in previous literature on experiences with homeownership for individuals with developmental disabilities. Further, it is important to recall that these participants were not selected at random; they were purposefully chosen by homeownership programs as representing especially successful examples of homeownership.

Homeownership for citizens with developmental disabilities is clearly achievable, and Home of Your Own projects established across the country have found innovative solutions to many of the financial and technical barriers faced by individuals with developmental disabilities seeking to own their own homes. However, long-term flexible support is essential to assisting individuals with developmental disabilities to enjoy the benefits of homeownership over time. It should not be expected that the supports connected with the initial home selection and purchase will remain in place indefinitely and continue to be adequate to address whatever circumstances arise in the future. Live-in caregivers will not live-in to eter-

nity, home modifications will break down or work better in theory than in practice, and people may change their minds and come to feel that their current home no longer meets their needs. The people in the network of relationships and services behind each homeowner must be able to respond in a person-centered way as problems arise and circumstances change, including giving people the option of selling a residence and purchasing another. This understanding of the evolving nature of housing support parallels the recognition in vocational services of the need for periodic assistance to consumers with job change and career advancement in place of indefinite job maintenance (Pumpian, Fisher, Certo, & Smalley, 1997).

Increased efforts are needed to ensure that the focus of assistance remains on the person's needs and goals—not the agency's or caregiver's—and considers how the person can best use their own capacities and resources (amplified by others) to solve their own problems and live their own lives. It is important to continue and expand efforts to make homeownership available to people with developmental disabilities, and part of this effort should include increased attention to building self-determination and person-centeredness into the ongoing support process.

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United States Court of Appeals,  
Sixth Circuit.

Mary Lue **SCHOTT**, Plaintiff-Appellee,  
Carol **LEVY**, Plaintiff Appellee/Cross-Appellant,  
v.

Janet **OLSZEWSKI**, in her capacity as Director of  
the Michigan Department of  
Community Health, and Marianne Udow, in her  
capacity as Director of the  
Michigan Family Independence Agency,  
Defendants-Appellants/Cross-Appellees.  
**No. 03-2490, 03-2536.**

Argued: Oct. 27, 2004.

Decided and Filed: March 15, 2005.

Appeal from the United States District Court for  
the Eastern District of Michigan at Detroit. No.  
96-75364--George E. Woods, District Judge.

Morris J. Klau, State of Michigan Department of  
Attorney General, Detroit, Michigan, for Appellants.

Jacqueline Doig, Center for Civil Justice, Saginaw,  
Michigan, for Appellees.

Before: **BOGGS**, Chief Judge; **GILMAN**, Circuit  
Judge; **SARGUS**, District Judge. [FN\*]

FN\* The Honorable Edmund A. Sargus,  
Jr., United States District Judge for the  
Southern District of Ohio, sitting by  
designation.

#### OPINION

**GILMAN**, Circuit J.

\*1 Mary Lue Schott and Carol Levy applied to Michigan's Medicaid program for coverage of their emergency hospitalization and medical bills. Schott's claims are not at issue in this appeal. Levy, however, paid for some of the services that she received while awaiting the long-delayed approval of her application. The state agencies administering the Medicaid program later refused to reimburse her

for the money she spent out-of-pocket for her medical care. Levy filed suit against the officials in charge of these state agencies, challenging both their failure to promptly pay her outstanding medical bills and their failure to reimburse her for her out-of-pocket payments made prior to being deemed eligible for Medicaid coverage.

In its final judgment, the district court required the state agencies to provide direct reimbursement to Levy for allowable services received during the statutory three-month retroactive-coverage period prior to her application for Medicaid. The court imposed several limitations, however, on the direct reimbursement. The state agencies now appeal the determination that they are required to provide direct reimbursement for allowable services received during the retroactive-coverage period. Levy cross-appeals the limitations imposed by the district court on the direct reimbursements.

For the reasons set forth below, we **AFFIRM** the judgment of the district court with respect to the requirement that the state provide direct reimbursement for the payment of allowable services received during the retroactive-coverage period, but **REVERSE** the judgment with respect to two of the limitations placed on these direct reimbursements.

#### I. BACKGROUND

Medicaid is a joint federal-state program that provides health insurance for low-income individuals. The program authorizes federal financial assistance to states that choose to reimburse certain medical expenses. State participation in Medicaid is optional, but once a state chooses to participate, it must adopt a plan that conforms to the requirements set forth in the Medicaid Act, *see* 42 U.S.C. § 1396, and its implementing regulations. Michigan's Medicaid program has been approved by the Centers for Medicare & Medicaid Services (CMS), the agency responsible for administering the program at the federal level and for assuring that states operate their programs in accordance with the approved

guidelines.

Levy applied for Medicaid to cover emergency hospitalization and medical bills in October of 1992. Her application was initially denied, but in December of 1995 the Saginaw County Circuit Court determined that Levy was eligible for Medicaid benefits for the period from August 1 to December 31, 1992. Between the initial denial of her application and the time that she was declared eligible for benefits, Levy paid over \$8,000 to cover some of the medical bills incurred during the retroactive-coverage period, but the bulk of her bills incurred during that time period--totaling more than \$40,000--remain unpaid.

\*2 Levy filed suit in November of 1996 against the officials in charge of the Department of Community Health and the Family Independence Agency, the state agencies that administer Michigan's Medicaid program. She challenged both the officials' failure to promptly pay her outstanding medical bills and their failure to reimburse her for her out-of-pocket expenditures made prior to being deemed eligible for Medicaid coverage.

In March of 2000, the district court held that otherwise-eligible Medicaid recipients were entitled to direct reimbursement for out-of-pocket payments made for Medicaid-covered services provided during the retroactive-coverage period. But the court deferred a ruling on Levy's motion for summary judgment regarding the expenses that she incurred during this period because it was uncertain whether she was otherwise eligible for Medicaid at the time she made her payments. It also declined to rule on the issue of whether the defendants had provided reasonably prompt assistance, requesting instead that the parties submit supplemental briefs addressing the applicable standard of care.

In September of 2003, after Levy had satisfied the district court of her Medicaid eligibility, the court issued its final judgment, which required the defendants to provide direct reimbursement to Levy for covered services received during the three-month retroactive-coverage period prior to her application for Medicaid. The district court, however, also imposed several limitations on the direct reimbursement. Specifically, the court required that the medical bills must have been paid

by the recipient (rather than by a third party) in order to be reimburseable. The court also determined that the reimbursement could be reduced by the amount that the out-of-pocket payments had depleted the recipient's assets in order to qualify for Medicaid. Finally, the district court may have limited reimbursement to the amount that Medicaid pays to participating providers, which is typically much lower than the rate paid by private individuals out-of-pocket, although the parties disagree as to whether the district court actually imposed this restriction.

The defendants now appeal the determination that they are required to provide direct reimbursement to Levy for allowable services received during the retroactive-coverage period. Levy cross-appeals the limitations imposed by the district court on the direct reimbursements. The claims for prompt payment of her medical bills are not at issue in this appeal.

## II. ANALYSIS

### A. Standard of review

This court reviews a district court's grant of summary judgment de novo. *Therma-Scan, Inc. v. Thermoscan, Inc.*, 295 F.3d 623, 629 (6th Cir.2002). Summary judgment is proper where there exists no genuine issue of material fact and the moving party is entitled to judgment as a matter of law. Fed.R.Civ.P. 56(c). In considering a motion for summary judgment, the district court must construe all reasonable inferences in favor of the nonmoving party. *Matsushita Elec. Indus. Co. v. Zenith Radio Corp.*, 475 U.S. 574, 587 (1986). The central issue is "whether the evidence presents a sufficient disagreement to require submission to a jury or whether it is so one-sided that one party must prevail as a matter of law." *Anderson v. Liberty Lobby, Inc.*, 477 U.S. 242, 251-52 (1986).

### B. Direct reimbursement

\*3 Pursuant to the Medicaid Act, Michigan's program must provide medical assistance to categorically and medically needy individuals. 42 U.S.C. § 1396a(a)(10). The categorically needy are those who are eligible for cash assistance because their income falls below a specific amount, § 1396a(a)(10)(A), whereas the medically needy are

those who have higher income levels but are still unable to pay for all of their medical needs, § 1396a(a)(10)(C). Under the Act, states must provide comparable medical assistance to all Medicaid recipients within each classification, so long as the medically needy do not receive greater benefits than the categorically needy (although the reverse is permitted). § 1396a(a)(10)(B).

The Act defines "medical assistance" as "payment of part or all of the cost of the [covered] care and services ... for individuals." § 1396d(a). It requires states to make medical assistance available for covered services provided to Medicaid recipients within the three months prior to the month in which the recipient applied for Medicaid (known as the retroactive-coverage period), provided that the recipient would have been eligible for Medicaid at the time the services were rendered. § 1396a(a)(34).

Levy, who qualifies for Medicaid because she is medically needy, alleges that she paid more than \$8,000 to her medical providers in the course of her efforts to obtain Medicaid coverage. She contends that the statutory regime requiring the states to cover services provided during the retroactive-coverage period obligates Michigan's Medicaid program to reimburse her for the amount she paid out-of-pocket. Michigan's failure to reimburse her, Levy argues, violates her right to medical assistance comparable to that received by medically needy individuals who do not pay their medical bills before Medicaid eligibility is established. *See* § 1396a(a)(10) ("[T]he medical assistance made available to any individual [covered by Medicaid] ... shall not be less in amount, duration, or scope than the medical assistance made available to any other such individual [within the same classification]."); 42 C.F.R. § 440.240(b) ("The plan must provide that the services available to any individual in [a covered medically needy group] are equal in amount, duration, and scope for all recipients within the group.").

But Michigan argues that, as a vendor-payment system, Medicaid makes payments to providers, not to recipients. Vendors participating in the Medicaid program agree to accept reimbursement from state Medicaid agencies at a rate significantly lower than the market rate in consideration of the certainty of

receiving payment. The states are permitted to make payments to individual beneficiaries only in limited circumstances. Specifically, the states have the option of making direct payments to medically needy recipients for services provided by physicians and dentists, § 1396d(a), but Michigan has not elected to exercise that option. (Individual beneficiaries who are categorically needy are not eligible for direct payments at all.)

\*4 Participating states are also allowed to directly reimburse individuals who make out-of-pocket payments for covered services if a state Medicaid agency improperly denies an individual's application for coverage. 42 C.F.R. § 431.246. Underlying this exception is the desire to correct the inequitable consequences of an erroneous denial of eligibility. At issue in this appeal is whether Levy is entitled to reimbursement for medical expenses incurred during the retroactive-coverage period before she applied for Medicaid. The district court granted summary judgment for Levy on the separate question of whether she was entitled to "corrective payments" under 42 C.F.R. § 431.246 for expenses incurred after her application was filed. That decision is not at issue in this appeal.

Courts that have considered whether medical bills incurred during the retroactive-coverage period are directly reimbursable to Medicaid recipients have found that payment is required. In *Blanchard v. Forrest*, 71 F.3d 1163 (5th Cir.1996), for example, the Fifth Circuit analyzed Louisiana's Medicaid program, which permitted direct reimbursement for expenses incurred during the retroactive-coverage period and initially paid out-of-pocket by the applicant, but only in instances in which the medical provider voluntarily refunded the applicant's payment and then submitted a claim evidencing the refund to the state Medicaid agency. The court noted that, because Medicaid rates are much lower than those charged to private patients, Medicaid providers in Louisiana have no incentive to initiate voluntary refunds to patients determined to be Medicaid-eligible after the services are rendered. *Id.* at 1167.

Under the Louisiana program, Medicaid applicants who failed to pay for services rendered during the retroactive-coverage period received a greater level of financial assistance than those who privately paid

for the services. The *Blanchard* court therefore concluded that Louisiana's program violated the statutory requirement that Medicaid coverage during this period should be just as effective as if the applicant had already been certified for coverage. *Id.* Even though the state agency had informed applicants in advance that they could not obtain retroactive assistance unless any advance payments were refunded by their providers, the court held that "the voluntary refund policy still fails to make available and effective medical assistance to all Medicaid applicants for supplies and services furnished during the retroactive-coverage period, as required by [§] 1396a(a)(34)." *Id.* at 1168.

Moreover, in a recent case with similar facts, the California Court of Appeals noted that

[e]very case brought to our attention in which the court was presented with an application for relief by a Medicaid recipient who had not received voluntary reimbursement for covered services obtained during the retroactivity period has provided relief. In some cases, the court has ordered the state agency to make reimbursement directly to the recipient.... Other cases have indicated that a state may also satisfy the comparability requirement by making reimbursement by the provider obligatory rather than voluntary.

\*5 *Conlan v. Bonta*, 102 Cal.App. 4th 745, 754 (2002) (holding that California's Medicaid program had failed to establish a process to ensure that recipients who had made out-of-pocket payments during the retroactive-coverage period were properly reimbursed). *See also Krieger v. Krauskopf*, 121 A.D.2d 448 (N.Y.S.Ct.1986), *aff'd without opinion*, 512 N.E.2d 540 (N.Y.1987) (holding that the petitioner was entitled to reimbursement for medical services covered by Medicaid that were received and paid for by the petitioner during the three-month period preceding the submission of her application). The decision of the district court below is therefore consistent with numerous federal and state court decisions that have previously addressed this issue.

In an attempt to distinguish the cases cited by Levy, the defendants point out that she tendered her payments not during the three-month time period in which she received medical treatment, but during

the period between the initial rejection of her application and its eventual acceptance on appeal. They argue that, to the extent direct reimbursement to recipients is appropriate, the purpose of the reimbursements is to protect individuals who make out-of-pocket payments for their care when they are either unaware of the Medicaid requirements or unable to apply for coverage. But after an application has been submitted, that purpose is no longer relevant because applicants are informed in a publication titled "Facts About Medicaid" that payments made directly to providers cannot be reimbursed. Levy's case is therefore arguably different from the cited cases in which the individuals paid for the services they received before applying for Medicaid coverage.

The district court found this reasoning unpersuasive. It concluded that the governing statutes and regulations do not require that payments be made prior to application in order to be reimbursable. Instead, the court determined that direct reimbursement is required where the following three conditions are met: (1) medical services were furnished during the three months prior to the recipient's application; (2) the services provided were covered under Medicaid; and (3) the recipient was eligible for Medicaid at the time the services were furnished. The court declined to find that the time of payment was dispositive. This reasoning is consistent with that of the Fifth Circuit in *Blanchard*, which held that notification to recipients that they would not be directly reimbursed absent a voluntary refund from their provider did not negate the fact that the policy itself violated the comparability requirement of the Medicaid Act. 71 F.3d at 1167. Thus, even though Levy may have been informed at the time of her application that she would not be reimbursed directly, Michigan's refusal to reimburse her out-of-pocket expenses nevertheless violates her right to be treated in the same manner as all other medically needy Medicaid recipients in Michigan.

\*6 We agree with the reasoning of both the district court and the Fifth Circuit. Direct reimbursement to Medicaid recipients who have paid out-of-pocket for medical services provided during the three-month period prior to their application for Medicaid is appropriate where, as here, the recipients were rejected for Medicaid coverage in

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the first instance. In Levy's case, for example, the process of establishing her eligibility took over three years. She in effect had no choice but to pay her providers at least in part during this period of time in order to continue receiving medical care. To then deny her reimbursement for expenses that would have been timely paid by Medicaid if her application had been initially accepted strikes us as inequitable, to say nothing of the state agencies' obligation to comply with the Medicaid Act's comparability requirement.

Reimbursement to Levy is also consistent with CMS's policy of making "direct reimbursement available to all individuals who pay for medical services between the date of an erroneous determination of ineligibility for Medicaid and the date that the determination is reversed." State Medicaid Manual § 6320. *See also* 42 C.F.R. § 431.246 (providing for corrective payments in the event of an incorrect denial of coverage, retroactive to the date the action was taken). The State Medicaid Manual provides that "[s]tates may make direct reimbursement to individuals who paid for covered services after an erroneous determination of ineligibility that is reversed on appeal. The purpose of this exception to the vendor payment principle is to correct the inequitable situation that results from an erroneous determination made by the agency." § 6320.2. In *Greenstein v. Bane*, 833 F.Supp. 1054, 1069 (S.D.N.Y.1993), the court held that 42 C.F.R. § 431.246 created an exception to Medicaid's vendor-payment regime because "[w]hen Medicaid needs to make corrective action, the provider has already been paid; it is only the recipient who requires reimbursement.... [I]f corrective payments were not made directly to the recipient, there would be no guarantee that he or she would actually be reimbursed for their [sic] payments." By grafting the logic underlying the corrective-payment principle onto *Blanchard*, *Conlan*, and *Krieger*, we are extending the holdings of these cases to cover reimbursement for payments made *after* the retroactive-coverage period, even though the services were provided *during* that period.

We wish to emphasize, however, the narrow scope of our holding. Levy's initial application for Medicaid was denied. Had she been accepted into the program from the outset, she would never have

been in a position where she felt the need to make payments for the medical services she received, because all of her care would have been covered by Medicaid. Our holding is therefore limited to Medicaid recipients who, like Levy, had their applications rejected when they first applied for Medicaid coverage and then were successful in having that adverse ruling overturned on appeal. We are not deciding whether an individual whose application is initially accepted but who nevertheless makes payments for medical care provided during the retroactive-coverage period is entitled to direct reimbursement.

\*7 As a final point on this issue, we find persuasive Levy's argument that the law as interpreted by the defendants leads to an unjust result. If direct reimbursement were unavailable to Medicaid recipients who had paid out-of-pocket for services provided during the retroactive-coverage period, then individuals who make a good-faith effort to pay by spending their scarce resources, incurring debt, or forfeiting other basic necessities to pay for needed care would not receive coverage except in the unlikely event that their medical providers choose to give them a refund and then seek payment from the state Medicaid program. Those individuals, on the other hand, who are able to obtain medical care without paying for it would receive complete coverage for the services provided. Interpreting the statute as the defendants suggest would therefore reward those who make no effort to pay for their own care and penalize those who do.

### C. Limitations on direct reimbursements

#### *1. The requirement that medical expenses be paid by the recipient*

The district court determined that direct reimbursement for medical expenses paid for care rendered during the retroactive-coverage period is available only if the charges were personally paid by the recipient. According to the court, the direct reimbursement must be reduced by the amount of any third-party payments made on the recipient's behalf. Such third-party payments include those made by family members, friends, and charitable organizations, as well as by those entities legally obligated to pay for the recipient's care.

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Medicaid is essentially a "payer of last resort," which means that it will not pay medical bills for which other parties are legally liable. *N.Y. Dept. of Soc. Serv. v. Bowen*, 846 F.2d 129, 133 (2d Cir.1988). It is, therefore, not obligated to reimburse recipients for medical bills paid by private insurers, Medicare, workers' compensation carriers, or parties liable as the result of personal injury claims. *See id.* But family members, friends, and charitable organizations have no legal obligation to pay for the medical needs of the poor and may expect to be repaid for their generosity in helping an individual receive needed medical care. *See Greenstein v. Bane*, 833 F.Supp. 1054, 1063-64 (S.D.N.Y.1993) (finding direct reimbursement appropriate for plaintiffs who had relied on charitable organizations or family members to pay their medical bills); *see also Cohen v. Quern*, 608 F.Supp. 1324, 1329-30 (N.D.Ill.1984) (drawing a distinction between an unobligated party who voluntarily pays a Medicaid recipient's bill and a third party who is legally obligated to make such payments for the purpose of determining the recipient's eligibility for Medicaid). The analysis of this issue in the above cases strikes us as well-reasoned. We therefore hold that the district court erred in not allowing reimbursement for medical bills paid by entities not legally obligated to make the payment.

2. *The requirement that reimbursements be reduced by the amount that the payments allowed the recipient to become eligible for Medicaid coverage*

\*8 The district court also allowed the defendants to deduct from direct reimbursements to individual recipients the amount of any "assets reduced by the payment of medical expenses by the recipient and/or Medicaid group member in order to establish asset eligibility ." Without such a limitation, recipients who lawfully dispose of assets by making payments for medical services to establish their financial eligibility for Medicaid would reap a windfall by later being reimbursed for their formerly excess assets.

This concept can best be illustrated with the following example: Suppose that an individual's countable assets must be less than \$2,000 to qualify for Medicaid. Someone with \$2,500 in assets would

obviously not qualify. But if that person paid \$750 to satisfy an outstanding bill for medical care provided during the previous three months and then promptly applied for Medicaid, his or her remaining assets of \$1,750 would be low enough to establish Medicaid eligibility. If that person, now a Medicaid recipient, were then reimbursed \$750 for the payments made during the retroactive-coverage period, he or she would recoup all of the assets disposed of to qualify for Medicaid in the first place. The \$750 reimbursement would thus result in a \$500 windfall for the individual. Instead, reimbursement should be limited to \$250, the amount that the individual paid out-of-pocket after spending down his or her assets to establish eligibility.

As the above example demonstrates, the avoidance of a windfall to Medicaid applicants is an appropriate consideration to take into account. We therefore conclude that the district court did not err in placing this limitation on the reimbursements.

3. *The requirement that reimbursements be limited to the Medicaid rate*

The parties disagree as to whether the district court further ruled that reimbursements should be available only at the Medicaid-payment rate, which is typically much lower than the rates charged to private-pay patients. This ambiguity is due to an inconsistency in the language of the judgment issued by the district court below. With respect to the "corrective-action" reimbursements (not at issue in this appeal), the judgment reads: "Reimbursement shall be for the recipient's out-of-pocket expenses ...." (Emphasis added.) But with respect to the issue of direct reimbursement for charges incurred during the retroactive-coverage period, the judgment reads:

Defendants shall reimburse payment for covered services received by the recipient in one or more of the three months prior to the recipient's Medicaid application ("retroactive period"), which were paid by the recipient who is eligible for Medicaid at the time the services were furnished.

The parties disagree as to the significance of the district court's failure to explicitly state that direct reimbursement for payment for services provided during the retroactive-coverage period should be for

out-of-pocket expenses, as it did in reference to the corrective-action reimbursements. Levy essentially argues that the court's failure to do so was simply an oversight, but the defendants contend that it was an indication that reimbursement was to be limited to the Medicaid rate. If in fact the court imposed such a restriction, however, we conclude that it erred in doing so.

\*9 On first impression, permitting reimbursement at the reduced Medicaid rate seems to provide a reasonable compromise to a complicated situation. Given that the medical services have been rendered and the provider already compensated, either the Medicaid recipient or the state Medicaid agency will unfortunately be forced to bear the differential cost. The recipient, who had to make payments in order to receive continuing care after being initially denied Medicaid coverage, will lose the money paid for the care if not reimbursed. Conversely, the state agency, which eventually accepted the recipient into the program, will lose if it is forced to pay at a rate higher than the Medicaid rate. Allowing reimbursement at the Medicaid rate is essentially a way of splitting the baby. The state agency would be in the same position that it would have been in had it paid the provider directly, whereas the recipient, while still not fully reimbursed, would recoup at least some of the money spent for medical care.

Two courts have in fact endorsed this compromise. One is the Supreme Court of Wisconsin, which held in *Keup v. Wisconsin Department of Health and Family Services*, 675 N.W.2d 755 (Wis.2004), that private-pay patients who are later found to be eligible for Medicaid are not entitled to be reimbursed by the provider for the amount paid out-of-pocket in excess of the Medicaid rate. The *Keup* court reasoned that because the plaintiff was neither a Medicaid applicant nor a recipient at the time she received treatment, the providers were entitled to charge her at their private-pay rate so long as she had notice of the applicable rate. 675 N.W.2d at 766. Similarly, the Court of Appeals of New York noted that "[t]he intent of the retroactive reimbursement provision of the federal statute is to provide financial assistance to those individuals who were unaware of their Medicaid eligibility. Nowhere in this statute is it required that, in this situation, the State make these individuals whole."

*Seittelman v. Sabol*, 697 N.E.2d 154, 158 (N.Y.1998).

Although the rationale of the *Keup* and *Seittelman* courts has an initial appeal, it does not address the fact that all of the arguments that support permitting direct reimbursement in the first place also support reimbursement at the out-of-pocket rate. Singling out a group of recipients for partial payment and providing full reimbursement to others violates the comparability provision of the Medicaid Act in the same way that distinguishing between those who paid for their care and those whose bills remain unpaid violates the provision. Where some Medicaid recipients are forced to pay for a portion of their treatment out-of-pocket while others are required to pay nothing for their treatment, the recipients have not received medical assistance of equal value. See *Greenstein v. Bane*, 833 F.Supp. 1054, 1074 (S.D.N.Y.1993); see also *Conlan v. Bonta*, No. 987697, slip op. (Cal Cal.Super. Ct. March 3, 2004) (enforcing *Conlan v. Bonta*, 102 Cal.App. 4th 745, 754 (2002), which held that the Medicaid compliance plan must fully reimburse participants for their out-of-pocket expenses); *Kurnik v. Dept. of Health & Rehabilitative Servs.*, 661 So.2d 914, 918 (Fl.Ct.App.1995) (holding that the plaintiffs were "entitled to be made whole for out-of-pocket expenditures made before eligibility is determined").

\*10 The Medicaid program, like all public benefit programs, requires a careful balancing of costs and benefits. *Seittelman*, 697 N.E.2d at 159. Both the financial integrity of the program and the needs of individual recipients must be considered. Failure to reimburse recipients for all of their expenses, however, shifts the burden of spiraling health care costs onto those who can least afford it, which is inconsistent with the very purpose of the Medicaid program. *Keup*, 675 N.W.2d at 775 (Abrahamson, J., dissenting). We therefore hold that direct reimbursements to those initially denied Medicaid coverage should not be limited to the Medicaid rate, but instead should be for the full out-of-pocket amount paid by the recipient.

If the state is unhappy with having to reimburse recipients at a rate higher than what it pays providers, it has the option of requiring that providers issue refunds to individuals who pay for

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services rendered during the retroactive-coverage period and then seek payment from Medicaid at the reduced rate. See 42 C.F.R. § 447.15 (requiring states to limit participation in Medicaid to providers who accept the Medicaid rate as payment in full); see also *Cohen*, 608 F.Supp. at 1330-32 (ordering providers to refund payments made by Medicaid recipients for services rendered during the retroactive-coverage period, but declining to order direct reimbursement because the state agency lacked the authority to issue payments to Medicaid recipients directly). Because Michigan has not elected to pursue this avenue of reimbursement for recipients, its Medicaid program should fully reimburse recipients such as Levy for their out-of-pocket payments.

### III. CONCLUSION

For all of the reasons set forth above, we AFFIRM the judgment of the district court with respect to the requirement that, 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. We also AFFIRM the judgment with respect to the requirement that reimbursements be reduced by the amount that the payments lowered the recipients' total assets to the level necessary to qualify for Medicaid. Finally, we REVERSE the judgment with respect to the requirement that the medical expenses are not reimbursable unless paid by the recipient personally and the presumed requirement that reimbursements be made at the Medicaid rate.

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## Status Report: Litigation Concerning Home and Community Services for People with Disabilities

October 3, 2005

### I. Introduction

The past seven years have seen a flood of lawsuits concerning home and community services for people with disabilities. Many lawsuits challenge state policies that limit access to Medicaid home and community services. Others aim at securing community services in the most integrated setting for institutionalized persons as provided by the Americans with Disabilities Act (ADA). Still others challenge state policies that prevent individuals with disabilities from accessing the full range of community services.

This periodic report tracks the status of lawsuits that revolve around home and community services for people with disabilities. We caution that the report is not necessarily inclusive of all lawsuits in this arena. The report tracks three broad categories of lawsuits:

- **Access to Medicaid Home and Community Services.** These lawsuits challenge state policies that prevent people with disabilities from promptly obtaining Medicaid home and community services. Most of these lawsuits involve people with developmental disabilities who are waiting for services. Individuals with other disabilities who

want but cannot obtain home and community services also have filed several lawsuits. The plaintiffs in these lawsuits include individuals who are in nursing or other facilities but want to return to the community as well as persons who face institutionalization absent community services.

- **Community Placement of Institutionalized Persons.** These lawsuits principally (but not exclusively) involve persons served in publicly-operated institutions who could be supported in the community.
- **Limitations on Medicaid Home and Community Benefits.** These lawsuits challenge state policies that affect the scope and quality of Medicaid services in the community. Some lawsuits concern the adequacy of state payments for community services. Others challenge state restrictions on services available through the Medicaid program.

In the following sections of this report, the issues that have prompted these lawsuits are discussed and the lawsuits are summarized, including their current status.

### II. Access to Medicaid Home and Community Services

#### A. Medicaid Home and Community Services

The Medicaid program underwrites more than one-half of the costs of long-term services for individuals of all ages. Because the Medicaid program looms so large in the provision of long-term services, it has attracted a high volume of litigation.

In the past and still today, the majority of Medicaid long-term dollars pay for institutional services in nursing facilities, intermediate care facilities for the mentally retarded (ICFs/MR) and other settings.

Federal Medicaid law (Title XIX of the Social Security Act) requires that every state include nursing facility services in its Medicaid program. Since 1971, states have had the option to offer ICF/MR services. Initially, ICF/MR services were concentrated in state-operated institutions. Now, the majority of ICF/MR residents are served by non-state providers and the number of public institutions has decreased. (Prouty *et al.*, 2004).

Medicaid home and community services include home health care, personal care/assistance provided as a

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Medicaid state plan benefit, and home and community-based services (HCBS) furnished under federal waivers. All states must provide home health in their Medicaid programs. States may elect to provide personal care/assistance and/or operate HCBS waiver programs.

The HCBS waiver program allows a state to offer community services as an alternative to institutional services (e.g., nursing facility and ICF/MR) to persons who meet institutional eligibility criteria. A state may offer services that it could but does not provide under its regular Medicaid program (e.g., personal care) and other services that cannot be offered as regular Medicaid benefits but aid individuals to remain in the community. Federal law (§1915(c) of the Social Security Act) allows a state to select the services that it offers in a waiver program and target waiver services to Medicaid beneficiary target groups (e.g., individuals with developmental disabilities). (ASPE, 2000) A state also can limit the number of persons who participate in an HCBS waiver program.

While institutional spending still dominates Medicaid long-term services, states have substantially boosted spending for home and community services. For more than a decade, spending for Medicaid home and community services has grown more rapidly than institutional services. Between 1994 and 2004, HCBS waiver expenditures increased about six-fold, reaching \$21.2 billion. The share of Medicaid long-term services expenditures devoted to home and community services was 36% in 2004 compared to a little over 10% in 1990.<sup>1</sup> In developmental disabilities services, HCBS waiver spending surpassed ICF/MR institutional spending in 2001.<sup>2</sup>

Several critical factors have prompted lawsuits to expand access by people with disabilities to Medicaid home and community services. The most important is that growing numbers of individuals with disabilities want to remain in and be supported in their own homes and communities rather than institutions. Despite the expansion of Medicaid home and community services, most states have not kept pace with upward spiraling demand for long-term services. (Smith, 1999) Demographic and other factors lie behind rising demand for community services. Since the supply of community services has not kept pace with demand,

the result has been wait listing individuals for services and a backlog of persons in nursing facilities and other institutional settings who cannot return to the community. Mounting frustration over the shortage of community services has boiled over into litigation.

Under Medicaid law, there is an entitlement to the institutional services included in a state's Medicaid program. The aim of the lawsuits is to establish that Medicaid beneficiaries with disabilities have access to community services on equal footing with "entitled" institutional services. Until seven years ago, there had been relatively little litigation concerning Medicaid home and community services. In the arena of developmental disabilities services, the 1998 11<sup>th</sup> U.S. Circuit Court of Appeals decision in the Doe v. Chiles lawsuit held that a state cannot simultaneously limit access to entitled ICF/MR services. This decision (described below) triggered lawsuits elsewhere to challenge state authority to restrict access to Medicaid services by people with developmental disabilities. In 1999, the U.S. Supreme Court issued its landmark Olmstead v. L.C. ruling that Title II of the American with Disabilities Act requires states to make diligent efforts to serve individuals in the most integrated setting. The decision sparked lawsuits to secure community services for institutionalized persons as well as others who potentially face institutionalization absent community services. While there are differences among the lawsuits, at heart their common theme is to ensure that individuals with disabilities who need long-term services can obtain them promptly in the community not just institutional settings.

## B. Legal Issues

Lawsuits in this category assert that federal Medicaid law obliges a state to furnish home and community services to eligible individuals when needed, challenging the premise that states have the authority to restrict the availability of these services. In many cases, the U.S. Supreme Court's Olmstead ruling also serves as the grounds for pleadings that the ADA dictates that states must furnish home and community services in the most integrated setting.

In most cases, these lawsuits have been filed in federal court, although a few have been filed in state court when violations of state law also are alleged. Federal Medicaid law does not specifically provide for a beneficiary's seeking relief through the federal courts for alleged violations of Medicaid law. Federal law requires that a state operate an administrative appeals process (called Fair Hearing) through which a person may appeal adverse decisions concerning eligibility or services. Otherwise, if a state does not comply with

<sup>1</sup> For information concerning 2004 Medicaid long-term services spending nationwide and by state, go to: [hcbs.org/browse.php/type\\_tool/129/ofc/30/](http://hcbs.org/browse.php/type_tool/129/ofc/30/)

<sup>2</sup> In 2004, HCBS waiver expenditures for persons with developmental disabilities reached \$15.5 billion compared to \$11.9 billion for ICF/MR services. There were about 425,000 HCBS waiver participants with developmental disabilities compared to 105,000 ICF/MR residents. (Prouty et al., 2005)

Medicaid law and regulations, the principal federal remedy is to withhold or deny payments to the state.

In order to bring suit in federal court, plaintiffs rely on provisions of the U.S. Constitution and/or federal law in seeking relief. In particular, the Civil Rights Act of 1871 (42 U.S.C. §1983) grants citizens a private right of action to seek relief in federal court when state officials are alleged to violate the Constitution or federal law. This Act has long served as the basis for bringing lawsuits in federal courts involving Medicaid services. Plaintiffs must seek prospective relief from alleged state violations of federal law and show that federal law confers an *individually enforceable right*.

Usually, these lawsuits also seek certification as a class action complaint because, in addition to the named plaintiffs who allege that their rights have been violated, there are other individuals in the same situation. Class action certification is the subject of a separate determination by the courts.

In defense, some states have claimed “sovereign immunity” from these lawsuits under the provisions of the 11<sup>th</sup> Amendment to the U.S. Constitution. The 11<sup>th</sup> Amendment bars suits against states in federal court. With rare exceptions, federal courts have rejected this defense in lawsuits involving Medicaid.

More recently, states have challenged the premise that Medicaid law confers individually enforceable rights that fall under the protections of §1983. These challenges are based on the 2002 U.S. Supreme Court Gonzaga University v. Doe decision that set forth more stringent conditions for bringing §1983 complaints. Relying on this decision, states have argued that federal Medicaid law only governs a state’s overall administration of its Medicaid program but does not grant beneficiaries individually enforceable rights.

Since the Gonzaga decision was handed down, there have been several decisions concerning whether Medicaid law confers individually enforceable rights.<sup>3</sup> Increasingly, federal courts are ruling that various provisions of Medicaid law do not confer such rights. Going forward, the fundamental question of whether individuals can seek relief through the federal courts for alleged violations of Medicaid law likely will continue to be litigated.

While claimed violations of federal Medicaid law vary by lawsuit, they often include:

- **Reasonable Promptness.** §1902(a)(8) of the Social Security Act (hereinafter, “the Act”) and associated

federal regulations mandate that a state promptly determine the eligibility of persons who apply for services. The regulatory standard for processing Medicaid applications for long-term care is no more than 90-days. Federal courts have ruled that §1902(a)(8) bars a state from wait listing individuals for entitled Medicaid services rather than providing them right away. In Doe v. Chiles, for example, the court held that this provision requires a state to furnish ICF/MR services promptly once an application has been approved and, thereby, wait-listing individuals indefinitely violates the intent of §1902(a)(8).<sup>4</sup>

- **Comparability.** §1902(a)(10) of the Act requires a state to make Medicaid services available on a “comparable” basis to all eligible individuals. In some lawsuits, plaintiffs claim that, by furnishing community services to some but not all eligible persons, a state violates this provision.
- **Freedom of Choice.** §1915(c)(2)(C) of the Act requires that a state afford an individual the freedom to choose between receiving waiver and institutional services. In some complaints, plaintiffs claim that, under §1915(c)(2)(C) of the Act, a person who meets eligibility requirements for institutional services has the right to select waiver services instead. In other words, a person’s eligibility for entitled institutional services translates into an entitlement for waiver services. But, pursuing this claim has run up against the authority of a state to limit the number of individuals served in HCBS waiver programs.
- **Right to Apply.** §1902(a)(3) of the Act affords individuals the right to apply for services and have a decision rendered concerning their applications. If a person’s application is denied, then the individual has the right to appeal. In some cases, plaintiffs argue that the practice of waiting listing individuals for services instead of determining their eligibility short-circuits this fundamental protection. Often, there is an accompanying claim that a state’s policies violate the Constitution’s due process protections.

Alleged violations of Medicaid law often are accompanied by claimed violations of Title II of the ADA and §504 of the Rehabilitation Services Act of 1973. Title II requires public entities to provide services in the “most integrated setting” appropriate to a person’s needs. Plaintiffs assert that Title II mandates that individuals have access to community services on equal footing with institutional services and, by making institutional but not community services available, a state violates the ADA. Claimed §504

<sup>3</sup> See Jane Perkins (2005) *Using Section 1983 to Enforce Federal Laws* available at: [healthlaw.org/library.cfm?fa=detail&id=76446&appView=folder](http://healthlaw.org/library.cfm?fa=detail&id=76446&appView=folder)

<sup>4</sup> This decision is at [laws.findlaw.com/11th/965144man.html](http://laws.findlaw.com/11th/965144man.html).

violations are similar except that this statute dictates that recipients of federal funds furnish services in the “least restrictive setting.”

The U.S. Supreme Court’s Olmstead decision<sup>5</sup> directly addressed Title II of the ADA. While the underlying litigation revolved around the denial of community placement of two institutionalized persons, the Court expressed the view that a state would not violate Title II if it had a “comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings” and “a waiting list that moved at a reasonable pace.” But, the Court qualified its decision by stipulating that a state would not be deemed to violate Title II if achieving compliance forced it to make a “fundamental alteration” in its programs. Courts are grappling with the question of what constitutes a fundamental alteration.<sup>6</sup>

### C. Lawsuits Involving Individuals with Developmental Disabilities

There has been a high volume of lawsuits that challenge wait listing individuals with developmental disabilities for Medicaid home and community services. States have experienced a substantial increase in the number of individuals seeking community services and have had difficulty keeping pace with this especially strong service demand. In addition, over the past several years, many states have limited or reduced ICF/MR services in favor of expanding waiver services. But, the total supply of ICF/MR “beds” and HCBS waiver “slots” often has not kept up with demand, resulting in individuals queuing up on waiting lists. In some states, waiting lists have grown quite large. States also have limited their expenditures by capping both the number of persons who receive waiver services and the number of ICF/MR beds. The combination of ICF/MR bed limits and HCBS waiver “slot” caps may mean that neither type of service is readily available to individuals. Waiting lists are a very visible problem in nearly all states, thereby explaining the large number of lawsuits to secure services for persons with developmental disabilities.

As noted, in March 1998, the 11<sup>th</sup> U.S. Circuit Court of Appeals handed down a watershed ruling in the Florida Doe v. Chiles litigation that made it clear that federal Medicaid law does not allow a state to wait list individuals for ICF/MR services indefinitely. Florida had sought to limit the availability of both ICF/MR

and HCB waiver services. The Court ruled that ICF/MR services were no different than any other non-waiver Medicaid service and, hence, must be furnished with reasonable promptness to eligible applicants. Also, the court rejected the state’s attempt to justify limiting services due to budget considerations, noting that courts had repeatedly found that “inadequate state appropriations do not excuse noncompliance.” The Doe decision triggered lawsuits elsewhere.

The 11<sup>th</sup> Circuit decision spoke directly to ICF/MR but not waiver services. Most developmental disabilities waiting list lawsuits have been filed by people who seek HCBS but are wait-listed. In many of these lawsuits, plaintiffs are attempting to establish the principle that a person’s eligibility for ICF/MR services also extends to “equivalent” or “ICF/MR level” services under the HCBS waiver program.

In the West Virginia Benjamin H litigation (described below), the district court confronted a situation where a state had placed a moratorium on the development of new ICF/MR beds, nearly all available HCBS waiver slots were filled and only persons in crisis were offered services. Other individuals had little or no prospect of receiving services in the near term. The court ruled that “Medicaid provides entitlements” and the state’s restrictions on services violated the reasonable promptness requirement. The court rejected the state’s defense that it lacked the funds to provide the services because, in the court’s view, allowing this defense would permit states to “easily renege on their part of the Medicaid bargain by simply failing to appropriate sufficient funds.” In short, the court found that the state could not impose limits on the total number of people who could receive ICF/MR or HCB waiver services. The court ordered the state to implement a plan to eliminate the waiting list and ensure that individuals could exercise free choice in selecting between institutional and community services.<sup>7</sup>

The Doe decision held that a state could not waitlist individuals for ICF/MR services and the Benjamin H decision spoke to when a state had cut off access by limiting both ICF/MR and HCB waiver services. Federal court rulings in some other lawsuits<sup>8</sup> have pointed in the same direction as the Benjamin H ruling; namely, a person’s eligibility for entitled ICF/MR services extends to home and community services. But, it is still far from settled that individuals who are not receiving services but qualify for ICF/MR services are entitled to HCBS.

<sup>5</sup> This decision is at [supct.law.cornell.edu/supct/html/98-536.ZS.html](http://supct.law.cornell.edu/supct/html/98-536.ZS.html). For more about the decision, go to the Atlanta Legal Aid Society website: [atlantalegalaid.org/impact.htm](http://atlantalegalaid.org/impact.htm)

<sup>6</sup> See Sara Rosenbaum and Joel Teitelbaum. (2004). *Olmstead at Five: Assessing the Impact*. Kaiser Commission on Medicaid and the Uninsured ([kff.org/medicaid/kcmu062104pkg.cfm](http://kff.org/medicaid/kcmu062104pkg.cfm)).

<sup>7</sup> See National Health Law Project (1999). “West Virginia Court Orders End to Home Care Waiting Lists” at [www.healthlaw.org/pubs/199907benjamin.html](http://www.healthlaw.org/pubs/199907benjamin.html).

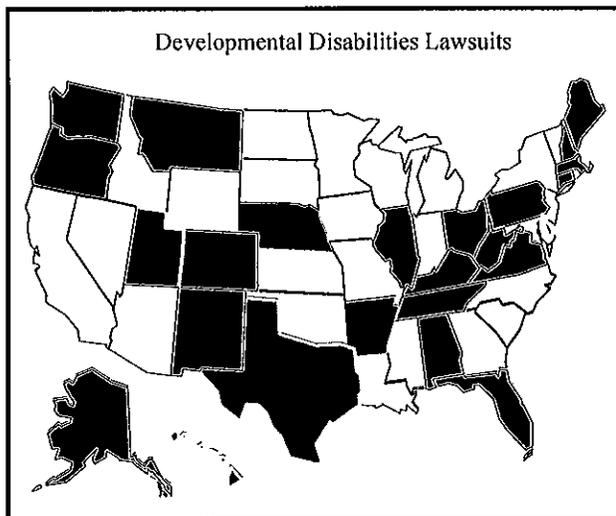
<sup>8</sup> E.g., Prado-Steiman et al. v. Bush (see below)

Developmental disabilities waiting list lawsuits vary with respect to the plaintiffs' situations and the services they seek. In particular:

- In many cases, the lawsuit involves individuals who receive no services at all and are seeking HCBS waiver services (e.g., KY, TN, UT);
- Other lawsuits involve persons who already participate in the waiver program but have been wait listed for or denied some services offered in the program, most often residential services (e.g., CT, MA, WA);
- In a few lawsuits, the plaintiffs seek ICF/MR services in small community group homes as opposed to HCBS (e.g., CO); and,
- In other lawsuits, plaintiffs also include individuals who reside in ICFs/MR or large public institutions who are seeking HCBS instead as well as persons in the community waiting for services (e.g., NM, TX)

### Status of Lawsuits

As of May 2005, lawsuits seeking community services for people with developmental disabilities had been filed in twenty-five states. Each lawsuit is summarized below. Presently, waiting list lawsuits in nine states (AL, CO, KY, NE, OH, TX, UT, WA) remain active. Settlements have been reached in thirteen lawsuits (AK, CT, DE, FL, HI, IL, ME, MA, MT, OR, TN, VA and WV). Four other cases (AR, NH, NM, PA) have been dismissed.



Settlement agreements spell out steps to resolve the central issues in a fashion satisfactory to each side. The court must approve the agreement after conducting a "fairness hearing." In the settlements, states typically have agreed to increase the number of individuals who receive Medicaid HCBS over a multi-year period (e.g., three to five years). Depending on the case, the agreement may address other issues.

Settlements also specify the circumstances that might void the agreement (e.g., not securing funds to implement the agreement), and how disputes will be resolved, including returning to court if need be.

### 1. Alabama: Susan J. et al. v. Riley et al.

This complaint (00-CV-918) was filed in July 2000 in U.S. District Court for Middle Alabama on behalf of plaintiffs with mental retardation. The lawsuit alleges that Alabama fails to furnish ICF/MR or HCBS waiver services to all eligible individuals but instead limits the number of persons who receive Medicaid long-term services and thus violates: (a) the requirement that services must be furnished with reasonable promptness per §1902(a)(8) of the Act; (b) the requirement that services be furnished to all eligible individuals on a comparable basis, as provided in §1902(a)(10)(B) of the Act; and, (c) the 14<sup>th</sup> Amendment to the U.S. Constitution by depriving individuals of their right to apply for services.

The state moved to dismiss the complaint, arguing that: (a) waiver services differ from other Medicaid services and, thus, are not subject to the same requirements; (b) states have the authority to limit the number of individuals served through an HCBS waiver program; and, (c) the plaintiffs have no enforceable right under federal or state law to the services they seek and, thereby, an action cannot be brought in federal court.

This lawsuit was quiet until recently. In June 2004, the court denied the state's motion to dismiss and ordered the state to answer the plaintiff complaint. In June 2005, the plaintiffs filed an amended complaint that expanded the number of named plaintiffs. In August 2005, the state answered the complaint, contending that the plaintiffs lacked standing to bring the lawsuit because they have no right to private action and claiming that the state is immune under the 11<sup>th</sup> Amendment to the U.S. Constitution. The parties are engaged in settlement discussions.

### 2. Alaska: Carpenter et al. v. Alaska Department of Health and Social Services

A private attorney filed this lawsuit on behalf of 15 individuals in January 2001 in the U.S. District Court for Alaska. The lawsuit asserted that Alaska violated federal Medicaid law, the ADA, §504 of the Rehabilitation Act, and the 14<sup>th</sup> Amendment to the U.S. Constitution by wait listing indefinitely eligible children and adults with developmental disabilities. The complaint argued that Alaska violated the ADA integration mandate as well as Medicaid's reasonable promptness requirement. The plaintiffs also alleged that Alaska violated federal requirements by improperly processing Medicaid applications and not

giving individuals the opportunity to appeal adverse decisions about service authorization or changes in services. The plaintiffs did not seek class certification. In March 2002, the Court accepted a stipulated agreement by the parties to dismiss the suit.

### **3. Arkansas: Tessa G. v. Arkansas Department of Human Services et al.**

Filed in June 2003 in the U.S. District Court for Eastern Arkansas, this lawsuit (03cv493) challenged Arkansas' practice of wait listing individuals for its HCBS waiver program for people with disabilities rather than allowing them to submit an application. In Arkansas, the state's practice had been to place individuals seeking services on a "request list." The lawsuit was not brought as a class action.

The plaintiff argued that the state violated §1902(a)(8) of the Act by denying her the opportunity to apply for services and have her application acted on promptly. The plaintiff also alleged violations of: (a) §1915(c)(2) of the Act for short circuiting her freedom to choose between ICF/MR and waiver services; (b) denying her access to the Medicaid Fair Hearing process under §1902(a)(3); and, (c) violating the procedural due process component of the 14<sup>th</sup> Amendment to the U.S. Constitution

At hearing, the court indicated that it was strongly inclined to order the state to provide an application to all individuals on the request list. The state conceded that federal law required that individuals be allowed to apply and have their applications acted upon promptly. It also agreed to offer waiver services to individuals on the request list up to its CMS approved participant cap. Reportedly, there were 1,000 available "slots" as a result of additional funding approved by the Arkansas legislature in its last session. Based on the state's willingness to voluntarily comply, the Court dismissed the case in August 2003.

### **4. Colorado: Mandy R. et al. v. Owens et al.**

Private attorneys filed this class action complaint (00cv01609) in the U.S. District Court for Colorado in August 2000. The complaint asserts that Colorado has violated federal Medicaid law, the ADA, §504 of Rehabilitation Services Act of 1973, and the U.S. Constitution by failing to provide ICF/MR residential services with reasonable promptness to eligible individuals. The plaintiffs specifically seek ICF/MR small group home services rather than waiver services. In Colorado, only a handful of individuals are served in ICFs/MR. Almost all individuals receive Medicaid residential services through the state's Comprehensive

Services HCBS waiver program. The Arc of Colorado supports this lawsuit.<sup>9</sup>

In March 2002, Judge Richard P. Matsch ruled on the accumulated motions in the case. His rulings on four motions were of particular interest. First, he denied the state's motion to dismiss the claim that Colorado is violating the §1902(a)(8) reasonable promptness requirement, relying on the opinion handed down by the 10<sup>th</sup> Circuit Court of Appeals in the New Mexico Lewis litigation (see below). Second, Matsch granted a motion by the Colorado Association of Community Centered Boards (CACCB) to intervene. CCBs are non-profit agencies designated in Colorado law to provide or arrange for community services for individuals with developmental disabilities. The CACCB intervened because the outcome of the litigation could have a substantial impact on CCBs. In its motion to intervene, the CACCB introduced a new claim that Colorado violates §1902(a)(30)(A) of the Social Security Act because the state's payments for community services are inadequate and caused their quality to erode. Under federal judicial rules, an intervener may raise new claims germane to the litigation. The CACCB also claimed that wait listing individuals violated federal Medicaid law. However, it argued that this violation should be remedied by expanding waiver services rather than ordering the state to furnish ICF/MR services.

Third, Judge Matsch denied the plaintiffs' motion to certify the complaint as a class action. Matsch ruled that the plaintiffs (who seek ICF/MR group home services) were not representative of the class as proposed (which would have included individuals who may want different types of services). Matsch also observed that, if the plaintiffs prevail, systemic change would follow, thereby making class certification unnecessary. Last, he denied the plaintiffs' motion for a preliminary injunction on two grounds. He pointed out that it was unclear that the plaintiffs would prevail on the merits. Second, he pointed out that the relief sought by the plaintiffs would cause major changes in the Colorado Medicaid program and have a major budgetary impact. Matsch decided that he did not have a basis to issue a preliminary injunction given its potential impact.

In July 2002, the state filed a motion to dismiss the plaintiffs' claims. The state argued that it had no affirmative responsibility to develop ICFs/MR but instead that its role was akin to an "insurer," limited to paying for services once delivered. In August 2002, the plaintiffs filed a motion for partial summary judgment. In their brief, the plaintiffs attacked the state's reasoning, arguing that the state's responsibilities

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<sup>9</sup> See statement at [thearcofco.org/waitinglist.html](http://thearcofco.org/waitinglist.html)

under Medicaid law extend beyond mere claims payment and include assuring that services are furnished to eligible persons. The plaintiffs asked the Court to summarily find the state in violation of §1902(a)(8) and §1902(a)(10) of the Act for failing to furnish ICF/MR services with reasonable promptness and providing them to some but not all eligible persons. The plaintiffs asked the Court to take up their ADA and §504 claims after deciding the ICF/MR entitlement question. Plaintiffs urged the court to apply the ADA and §504 to remedy the alleged Medicaid Act violations by ordering the state to sponsor the development of small ICF/MR group homes that meet the ADA integration standard.

In September 2003, Judge Matsch ruled on the outstanding summary judgment motions. He denied the plaintiffs' motions for summary judgment. At the same time, he denied the state's motion to dismiss the plaintiffs' claims that Colorado has violated §1902(a)(8) and §1902(a)(10) of the Social Security Act. These claims are at the center of the question of whether Colorado's policies violate Medicaid law. Matsch also denied the state's motion to dismiss the CACCB claim that Colorado's payments for community services violate §1902(a)(30).

But, Matsch dismissed the plaintiffs' ADA Title II and §504 claims, ruling that these claims were not "viable" and rejecting the plaintiffs' argument that Colorado's policies run afoul of the *Olmstead* decision, pointing out that "*Olmstead* does not stand for the proposition that a state must create, expand, or maintain programs for the purpose of preventing disabled individuals from becoming institutionalized." He also rejected the plaintiffs' proposition that he should consider the plaintiffs' ADA and §504 claims when fashioning remedies for the Medicaid violations, ruling that each claim must stand on its own merits.

Trial took place in early June 2004. Finally, in February 2005, Judge Matsch dismissed the plaintiffs' and CACCB intervenor claims.<sup>10</sup> In the end, Matsch decided that he could not order the relief that the plaintiffs sought because it would amount to mandating that the state provide or actively develop ICF/MR services. Such an order, Matsch reasoned, would have the effect of his ordering an increase in state taxes or appropriations and/or cause the state to withdraw services from its Medicaid program, actions that would be tantamount to "an exercise of federal judicial authority [that] would encroach upon the fundamental powers of the State government" and undermine the "no more fundamental principle of

democratic government than that which reserves to the people the power to tax and spend."<sup>11</sup> He decided that "the court cannot order the State to provide any particular level of ICF/MR services or to continue them in its State Plan."

In March 2005, the Mandy R plaintiffs and CACCB each appealed the dismissal to the 10<sup>th</sup> Circuit (05-1150 and 05-1148, respectively). The Circuit has consolidated the appeals for procedural purposes.

In September 2005, the Mandy R plaintiffs and the CACCB filed their appellant briefs. Each sharply criticized the district court's reasoning in dismissing the lawsuit due to its potential impact on Colorado's budget, arguing that it is well established that a state must provide sufficient funding to implement its Medicaid program. The Mandy R plaintiffs reasserted that Colorado is violating Medicaid law by not furnishing ICF/MR services with reasonable promptness and by not making such services available on a comparable basis to all Medicaid beneficiaries who require them. They further argued that the state's position that it merely functions an "insurer" and thereby has no affirmative responsibility to furnish Medicaid services to eligible individuals is contrary to fundamental Medicaid statutory requirements. The plaintiffs also asked the Circuit to review the denial of class certification, which the Circuit had previously declined to review.

The CACCB brief advanced many of the same arguments. The brief, however, argued that Colorado could meet the needs of the plaintiffs by substituting HCBS waiver for ICF/MR services, a position with which the Mandy R plaintiffs disagree. The CACCB asserted that the district court had not properly considered the claims regarding the inadequacy of the state's payments for waiver services. The CACCB also argued that the recent 9<sup>th</sup> Circuit ruling in the California *Sanchez v. Johnson* lawsuit (see below) is at odds with other U.S. Supreme Court decisions and should not serve as the basis for the 10<sup>th</sup> Circuit's rulings with respect to the payment issues raised by the CACCB. The state has not yet filed its brief with the Circuit Court.

<sup>10</sup> The decision is located at: [thearcofco.org/documents/MandyRvOwensMatschDecision.pdf](http://thearcofco.org/documents/MandyRvOwensMatschDecision.pdf)

<sup>11</sup> Colorado has a constitutional tax and expenditure limitation (known as the TABOR amendment) which dictates that government expenditures and revenues not increase at a rate faster than inflation and population growth. Judge Matsch reasoned that ordering the relief that plaintiffs sought would require overriding this limit. The plaintiffs argued that the limit could be exceeded as necessary to comply with a federal court order.

## 5. Connecticut: Arc/Connecticut et al. v. O'Meara and Wilson-Coker

This complaint (01-cv-1871) was filed in October 2001 in U.S. District Court for Connecticut by Arc/Connecticut against the Commissioners of the Departments of Mental Retardation (DMR) and Social Services (the state's Medicaid agency) on behalf of persons with mental retardation wait-listed for Medicaid home and community-based waiver services. The plaintiffs include persons who receive some waiver services but are wait listed principally for residential services and persons who do not receive any waiver services at all.

The lawsuit challenges several state policies. A central issue is plaintiffs' allegation that Connecticut has restricted waiver services based on available funding. The plaintiffs argue that this practice violates federal policy which requires that waiver participants receive the full range of services offered in a state's program that are necessary to meet their needs. The state is alleged to have wait listed individuals who receive day and other supports for waiver residential services. In support, the plaintiffs pointed to January 2001 policy guidance contained in the Centers for Medicare and Medicaid Services (CMS) Olmstead Letter #4.<sup>12</sup> Among its provisions, the CMS letter spelled out the requirement that waiver participants must be furnished any covered service that they require within a reasonable period. The plaintiffs also allege that the state masks the operation of the waiver in a fashion that results in individuals and families not being allowed to apply for the program and thus leaving them unaware of its benefits. Finally, the plaintiffs argue that, unless Connecticut is directed to change how it operates its program, individuals face the prospect of waiting years for services.

In January 2003, the court granted class certification, thereby expanding the lawsuit's scope to all 1,700 individuals on the state's waiting list. The class includes all persons eligible for DMR services who have applied for and are eligible for the waiver program or would be eligible if they had the opportunity to apply. In February 2003, the plaintiffs filed a second amended complaint.<sup>13</sup> The second amended complaint alleges that the state has violated: (a) §1902(a)(10)(B) of the Act by not making Medicaid services available on a comparable basis to all eligible persons; (b) §1902(a)(8) by not furnishing services with reasonable promptness and denying persons the opportunity to apply; (c) §1915(c)(2)(C) by not giving individuals a choice between institutional and waiver services; (d)

§1915(c)(1) and §1915(c)(4) for limiting services under the waiver program to those available and funded rather than providing the services needed by each person; (e) the ADA by not permitting ICF/MR residents to apply for the waiver program until they already have been placed in the community and operating its Medicaid program in a way that does not afford equal access to covered benefits; (f) §1902(a)(3) for not giving individuals the opportunity to appeal decisions concerning their services; and, (g) the plaintiffs' due process protections under the U.S. Constitution.

In August 2004, the state filed a motion to throw out the plaintiffs' claims. The state contended that the issues in this litigation were no different than those settled in a similar case (*Birks v. Lensink*) about ten-years ago which established the state's current priority waiting list system. The state also argued that the Medicaid Act does not confer individually enforceable rights on the plaintiffs, especially with respect to HCBS waiver services. The state also questioned the applicability of the ADA, contending that the ADA cannot serve as the basis for requiring a state to expand services and that the integration mandate only applies to institutionalized persons.

In late 2004, the parties arrived at a settlement agreement. In February 2005, the Connecticut legislature agreed to underwrite the costs of the settlement. On March 31, 2005, the parties submitted the agreement to the court.<sup>14</sup> The court approved the agreement and dismissed the lawsuit in May 2005. The agreement provides for the following:

- The class includes persons who have been found eligible for DMR services and (a) have applied for and been found eligible for waiver services or (b) would be eligible for services had they had a reasonable opportunity to apply;
- Over the five-year period commencing in the current state fiscal year and ending in FY 2009, the state agreed to expand its HCBS waiver programs each year to accommodate 150 persons per year at an average annual cost of \$50,000 per person and furnish family support services to an additional 100 persons per year at an average cost of \$5,000 per person. Over the five-year period of the settlement, Connecticut committed to expend an additional \$41 million in state funds to underwrite the settlement. Persons with urgent or high priority needs will have priority for waiver services;
- The state agreed to implement a new Individual and Family Support HCBS waiver that will offer flexible supports, incorporate self-direction, and

<sup>12</sup> Located at: [cms.hhs.gov/states/letters/smd11001.pdf](http://cms.hhs.gov/states/letters/smd11001.pdf)

<sup>13</sup> Located at: [arcct.com/WaitingListComplaint0203.htm](http://arcct.com/WaitingListComplaint0203.htm).

<sup>14</sup> The agreement, is at: [dmr.state.ct.us/WLSettlement.htm](http://dmr.state.ct.us/WLSettlement.htm)

complement the “comprehensive services” offered under the state’s existing waiver.<sup>15</sup> The state also agreed to revamp its current waiver program, including providing for independent service brokers; and,

- The state also committed to revamp its procedures to ensure that individuals have the opportunity to apply for waiver services, are provided information about such services, and receive a prompt determination of their eligibility for such services.

#### 6. Delaware: *The Arc of Delaware et al. v. Meconi et al.*

In April 2002, nine individuals – joined by The ARC of Delaware, Homes for Life Foundation, and Delaware People First – filed a class action complaint (02-cv-255) against the Delaware Department of Health and Social Services and its Division of Developmental Disability Services (DDDS) in the U.S. District Court for Delaware. The lawsuit charged that Delaware failed to serve more than 1,180 individuals who were eligible for but denied Medicaid HCBS waiver and/or community ICF/MR services. The Public Interest Law Center of Philadelphia and Community Legal Aid Society Disability Law Program (Delaware’s P&A agency) represented the plaintiffs.

The plaintiffs included individuals who live with aging caregivers along with residents of Stockley Center (Delaware’s public institution) assessed as appropriate to return to the community. The complaint alleged that these individuals have waited many years for services but had little prospect of receiving them any time soon. The proposed class included: (a) all individuals on the DDDS’ waiting list for community residential services; (b) all individuals receiving DDDS services eligible for but not receiving HCBS waiver or ICF/MR services; and, (c) all institutionalized persons who qualified for services in the community.

The plaintiffs argued that Delaware operates its service system in violation of Medicaid law, the ADA and the U.S. Constitution, thereby leading to the “denial of necessary care and services, inappropriate placement in state institutions, restraint [of] ... liberty without due process, unnecessary and needless deterioration and regression in health status, the loss of opportunities to maximize self-determination and independence, and the loss of opportunities to live in integrated settings and to receive programs and services development in accordance with professional standards.”

The plaintiffs claimed that Delaware violated: (a) §1902(a)(8) of the Act by failing to provide Medicaid

services with reasonable promptness and denying individuals the opportunity to apply for services; (b) Title II of the ADA and §504 of the Rehabilitation Act by not furnishing services in the most integrated setting. The complaint also alleged that Delaware does not have a “comprehensive effectively working plan” for placing qualified persons in less restrictive settings and was not moving its waiting list at a reasonable pace, as provided by the *Olmstead* decision; (c) §1902(a)(10) of the Act by not providing Medicaid services in adequate amount, duration and scope; (d) the Due Process Clause of the 14<sup>th</sup> Amendment to the Constitution and 42 U.S.C. §1983; and, (e) §1915(c)(2)(C) of the Act by not providing a choice between ICF/MR or waiver services.

In September 2003, the parties announced that they had arrived at an agreement to dismiss the lawsuit. In April 2004, the plaintiffs submitted a notice of dismissal to the court, based on a Memorandum of Understanding (MOU) agreed to by the parties. The MOU provides for the state to fund 79 new community residential placements in FY 2005, including placements for 24 Stockley residents. It also provides that the state will add a new waiver program to provide supports for persons who live with their families. The agreement also commits the state to collaborate with the plaintiffs to improve waiting list management and needs assessment as well as take other steps to strengthen community infrastructure. The MOU provides that the state will place additional Stockley residents in the community and seek increased funds to expand home and community services. In August 2004, the court approved the settlement.

#### 7. Florida: *John/Jane Doe v. Bush et al./Wolf Prado-Steiman et al. v. Bush et al.*

In 1992, a class action complaint was filed (as *Doe v. Chiles et al.*) on behalf of individuals who had been wait-listed for ICF/MR services. The *Doe* complaint asserted that Florida violated federal Medicaid law by not furnishing ICF/MR services with reasonable promptness to eligible Medicaid recipients with developmental disabilities. In March 1998, the U.S. 11<sup>th</sup> Circuit Court of Appeals upheld the District Court’s 1996 ruling that wait listing individuals for ICF/MR services violated federal Medicaid law (see above). A second complaint – *Prado-Steiman* (98cv06496) – was filed by The Advocacy Center (Florida’s P&A agency). This complaint directly challenged Florida’s policies in operating its HCBS waiver program for people with developmental disabilities (especially by not furnishing needed services) and was amended to contest the state’s wait listing individuals. In August 2001, the District Court approved a settlement agreement in the

<sup>15</sup> This waiver has been submitted to and approved by CMS. For more information, go to: [dmr.state.ct.us/HCBS/index.htm](http://dmr.state.ct.us/HCBS/index.htm)

Prado litigation that provided that all individuals waiting for services in July 1999 would receive services by 2001 and for the state to make substantial changes in the operation of its waiver program.

Led by Governor Jeb Bush, Florida has undertaken a major expansion of its HCBS waiver program for people with developmental disabilities. Since Bush took office in 1998, funding for developmental disabilities services has tripled and now exceeds \$1 billion. Between 1998 and 2001, the number of persons participating in Florida's waiver program for people with developmental disabilities doubled from 12,000 to 24,000. Among its other provisions, the Prado settlement agreement includes an "operational definition" of how the state will comply with the reasonable promptness requirement.

While Florida has made major strides in expanding community services, new issues have arisen since the settlement was reached, including the emergence of a "post-Prado" waiting list that reportedly has reached 15,000 individuals. These individuals sought services after July 1999 and, hence, are not covered by the settlement.

In March, 2002, the Advocacy Center filed a 20-page Notice of Material Breach of the Prado settlement, contending that systemic problems have led to the authorization of services that are "less than necessary to provide services in the community and in small facilities." The letter outlined deficiencies in the Florida service system in eighteen areas including: provider development and access in various geographic areas, quality assurance, service delivery timelines, and due process. Florida's Office of the Attorney General denied that the state had broken the terms of the agreement in "any material or systemic way." Following attempts to mediate the issues, in July 2003 the Advocacy Center moved that the court to continue its jurisdiction, based on material breach of the settlement agreement. In March 2004, the court rejected the plaintiffs' motion, finding that none of the alleged breaches warranted the court's continued jurisdiction.

#### **8. Hawai'i: Makin et al. v. State of Hawai'i/The Disability Rights Center et al. v. State of Hawai'i et al.**

**Makin.** In December 1998, the Hawaii Disability Rights Center – state's P&A agency – filed this class action complaint (98cv997) on behalf of 700 wait-listed individuals in the U.S. District Court for Hawai'i. The complaint alleged that the state's practice of wait listing individuals for HCB waiver services violated federal Medicaid law and the ADA. The state challenged the applicability of the ADA, arguing that the U.S. Supreme Court's Olmstead decision dealt

with only institutionalized persons. The district court rejected this argument by reasoning that the lack of community services would leave institutionalization as the only option available to individuals.

In April 2000, the state and plaintiffs forged a settlement agreement<sup>16</sup> wherein the state agreed to increase the number of individuals served in the state's HCBS waiver program by approximately 700 individuals over the three-year period ending June 30, 2003. By June 2002, approximately 560 additional individuals had been served. The agreement also provided that the state would not change its eligibility policies but would make other changes, including employing person-centered planning methods to identify the supports that individuals should receive.

**Disability Rights Center.** In September 2003, the Disability Rights Center completed its evaluation of the implementation of the settlement agreement. As a result of this evaluation, the Center filed a new class action complaint (03-00524) seeking declaratory and injunctive relief based on its view that the state has not complied with the Makin settlement agreement.<sup>17</sup> In essence, the Center alleges that the state policies and practices have caused 300 Makin class members class to remain on the waiting list. The Center contends that the state furnished services to individuals who sought services after the settlement agreement rather than to the class members and, in FY 2002, reverted funds that could have been used to serve the class members. Moreover, the Center argues that some class members are not receiving the full range of services that they require. The plaintiffs claim that the state's policies and practices violate: (a) the ADA; (b) §504 of the Rehabilitation Act; (c) the Constitution's procedural due process provisions; (d) §1902(a)(8) of the Act; (e) §1915(c)(2)(A) by furnishing inadequate waiver services; and, (f) provisions of Hawai'i state law. The plaintiffs are asking the court to order the state to move individuals – including class members – off the waiting list at a reasonable pace, defined as furnishing services to them within six months and also rule that the state's failure to adopt a comprehensive plan that assures the waiting list moves at a reasonable pace is unlawful. The parties are in settlement discussions.

#### **9. Illinois: Bruggeman et al. v. Blagojevich et al.**

This lawsuit (00-cv-5392) was filed in September 2000 by a private attorney in the U.S. District Court

<sup>16</sup> The lawsuit and agreement are at [hawaiidisabilityrights.org/General\\_NewsDetail.aspx?nid=1009](http://hawaiidisabilityrights.org/General_NewsDetail.aspx?nid=1009).

<sup>17</sup> At: [hawaiidisabilityrights.org/Forms/SMComplaint10.01.03\(web\).doc](http://hawaiidisabilityrights.org/Forms/SMComplaint10.01.03(web).doc). A press release describing the complaint is at: [hawaiidisabilityrights.org/General\\_NewsDetail.aspx?nid=1018](http://hawaiidisabilityrights.org/General_NewsDetail.aspx?nid=1018)

for of Northern Illinois on behalf of five named plaintiffs with developmental disabilities eligible for but not receiving Medicaid long-term services. The complaint alleged that Illinois did not furnish Medicaid services with reasonable promptness nor afford individuals freedom of choice to select between ICF/MR and HCB waiver services. The suit also alleged violations of other provisions of the Social Security Act, the ADA, §504 of the Rehabilitation Act and the 14<sup>th</sup> Amendment to the U.S. Constitution. The plaintiffs asked the court to "issue preliminary and permanent injunctive relief requiring the Defendants ... to offer the Plaintiffs the full range of ICF/MR services or HCB waiver services and other services for which they are eligible within 90 days or some other specifically defined, reasonably prompt period."

In response, the state moved to dismiss, claiming immunity under the 11<sup>th</sup> Amendment and challenging the plaintiffs' other claims. In May 2001, siding with the state, the court dismissed the plaintiffs' ADA claim because the complaint was filed against public officials whereas Title II of the ADA speaks to the policies of a "public entity." However, the court rejected the state's arguments concerning the other claims, including sovereign immunity.

In February 2002, the court dismissed the lawsuit, deciding that the plaintiffs' main claim was their lack of access to residential services near their families. The court was persuaded by the state's arguments that (a) federal law does not require that a state arrange for services on the basis of proximity to family and (b) the services the plaintiffs sought might be available elsewhere in Illinois. The court also ruled that the plaintiffs lacking standing to bring the lawsuit.

In March 2002, the plaintiffs appealed the dismissal to the 7<sup>th</sup> Circuit Court of Appeals. The plaintiffs asked the Circuit to review the district court's rulings on the Medicaid, ADA, and Rehabilitation Act claims and argued that facts unearthed during trial showed that the state was not in compliance with federal law. In June 2002, the U.S. Department of Justice (USDOJ) Civil Rights Division submitted an *amicus* brief. The brief focused only on the district court's dismissal of the ADA claim. The brief noted that the dismissal was based on a previous 7<sup>th</sup> Circuit ruling that USDOJ contended was in error. USDOJ argued that there was ample support for the proposition that individuals may sue public officials not just public entities in federal court to enjoin violations of the ADA.

In July 2002, another *amicus* brief was filed by the American Civil Liberties Union (ACLU) of Illinois, Equip for Equity (the Illinois P&A agency), and a coalition of Centers for Independent Living. This brief

also argued for reinstating the ADA claim and that the district court paid insufficient attention to the interplay of Illinois' policies and their impact on access to services in the most integrated setting in dismissing the ADA claim. The brief urged the Circuit to "leave for another day the many larger legal questions ... regarding whether the Illinois system for providing services ... complies with federal law."

In October 2002, the state replied, again arguing that the plaintiffs lacked standing to bring suit and also that there was no enforceable federal requirement that individuals receive services in close proximity to their families. Next, the defendants asserted that their only responsibility under federal Medicaid law was to "provide appropriate rates of payment" but not to ensure that individuals receive necessary services. Finally, the state asserted that it had not waived 11<sup>th</sup> Amendment rights and urged dismissal of the lawsuit on sovereign immunity grounds.

In April 2003, the Circuit held that the district court erred in finding that the plaintiffs lacked standing to pursue their Medicaid claims but upheld the lower court decision to reject these claims, ruling that federal law did not dictate that services be available near the individual's family home. The Circuit also conceded that its prior ruling that suits brought under the ADA must be filed against public entities rather than state officials had been in error, based on decisions elsewhere.

But, the Circuit ruled that the district court erred in ruling that the plaintiffs lacked standing to sue under the Rehabilitation Act. The Circuit set aside the dismissal of the plaintiffs' Rehabilitation Act and ADA claims. The Circuit remanded the lawsuit and "commended" to the district court the Olmstead decision, especially pointing to that part of the decision that provided "if... the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated," the state would not be violating Title II.<sup>18</sup>

In July 2004, the parties announced that they had arrived at a stipulated settlement of the lawsuit. The details of this settlement are not available but reportedly it is limited to providing services to the named plaintiffs. The court then dismissed the case.<sup>19</sup>

<sup>18</sup> The opinion is on the 7<sup>th</sup> Circuit's web site at: [ca7.uscourts.gov/op3.fwx](http://ca7.uscourts.gov/op3.fwx). Enter case number 02-1730.

<sup>19</sup> A new lawsuit has been filed in Illinois concerning access to residential services. See in Part IV of this report.

**10. Kentucky: Michelle P et al. v. Holsinger et al.**

In February 2002, the Kentucky Division of Protection and Advocacy filed a lawsuit (02-CV-00023) in the U.S. District Court for Eastern Kentucky on behalf of four people with mental retardation and their family caregivers against the Cabinet for Health Services along with the Departments for Medicaid Services and Mental Health and Mental Retardation. The lawsuit charges that Kentucky has improperly wait listed individuals for Medicaid services.<sup>20</sup> The plaintiffs also sought class certification on behalf of an estimated 1,800 wait-listed persons. In recent years, the Kentucky legislature has substantially boosted funding in order to reduce the waiting list but a long waiting list persists.

The plaintiffs argue that, even though they are eligible for ICF/MR level services, they have been wait-listed and have indefinite prospects for receiving services. They also complain that even individuals in emergency status are unable to receive services promptly despite their priority status. The complaint claims that Kentucky is violating: (a) §1902(a)(10)(A) of the Act for failing to provide ICF/MR level services to all Medicaid beneficiaries who are eligible for them; (b) §1902(a)(8) for failing to furnish services with reasonable promptness; (c) §1902(a)(10)(B) for making ICF/MR level services available to some Medicaid beneficiaries but not all; (d) Title II of the ADA and §504 of the Rehabilitation Act by failing to serve individuals in the most integrated setting; and, (e) §1915(c)(2)(C) by not giving eligible individuals a practical choice between ICF/MR or other available alternatives through the HCBS waiver program.

In March 2002, the District Court granted class certification and ruled in plaintiffs' favor on other motions over state objections. The class is "all present and future Kentuckians with mental retardation and/or related conditions who live with caretakers who are eligible for, and have requested, but are not receiving Medical Assistance community residential and/or support services." In June 2002, the 6<sup>th</sup> Circuit Court of Appeals denied the state's petition appealing the class certification. Trial was scheduled for January 2005.

However, in December 2004, the state filed a last-minute motion to dismiss, thus delaying the start of trial. The court turned down this motion on February 11, 2005. Kentucky P&A reports that the court "upheld our position on every provision of Medicaid law that we alleged in our case. In addition, the Court ruled that

our claims under the Americans with Disabilities Act (ADA) and Section 504 were still viable. It also ruled that the state's attempt to limit the Olmstead ruling to people in institutions was misplaced."

In particular, the court affirmed that federal Medicaid law *unambiguously* confers individually enforceable rights under the provisions of §1902(a)(10)(A), §1902(a)(8) and §1915(c)(2)(C) and that §1905(a)(15) – in combination with other provisions – confers an individually enforceable right to ICF/MR services. The court also rejected the state's arguments to throw out the ADA and §504 claims. The parties are in settlement discussions. Trial has been postponed until March 2006.

**11. Maine: Rancourt et al. v. Maine Department of Human Services et al.**

In August 2001, a complaint (01-CV-00159) was filed in the U.S. District Court for Maine on behalf of three adults with developmental disabilities waiting for services was filed against the Maine Departments of Human Services (the Medicaid agency) and Behavioral and Developmental Services (which administers Maine's HCBS waiver program). The lawsuit charged that the state did not furnish services to people with developmental disabilities in a "reasonably prompt" manner. Class-action certification was sought on behalf of 1,000 adults with developmental disabilities who were not receiving timely services.

In November 2001, the court denied the state's motion to dismiss the lawsuit on 11<sup>th</sup> Amendment sovereign immunity grounds. The court portrayed the state's arguments for dismissal as "while intellectually intriguing, are a didactic exercise in historical legal formalisms, apparently inspired by the musings of Justice Scalia ...." The Court pointed to previous 1<sup>st</sup> Circuit decisions that affirmed federal court jurisdiction in these types of lawsuits. In May 2002, the Court certified the class action over the state's objections. The state petitioned the 1<sup>st</sup> Circuit to review the class action certification. In July 2002, the 1<sup>st</sup> Circuit rejected the petition.

In May 2003 the parties filed a joint motion asking the court to approve a settlement that they had worked out. In July 2003, the court approved the agreement.<sup>21</sup> The agreement is effective January 2004 and the court will retain jurisdiction through December 2006. For purposes of the agreement, the class is defined as: "all developmentally disabled individuals who: (1) are current or future recipients of Medicaid in the State of Maine; (2) are no longer entitled to receive benefits

<sup>20</sup> More information is at [kypa.net/community/Olmstead/waitinglist\\_1.html](http://kypa.net/community/Olmstead/waitinglist_1.html).

<sup>21</sup> A description of the agreement and its full text are located at: [drcme.org/rancourt.html](http://drcme.org/rancourt.html)

and services through the Maine public school system; and (3) are eligible to receive intermediate care facilities and/or other services for the mentally retarded, or care under the Home and Community-Based Waiver Services for Persons with Mental Retardation.”

The agreement provides that the state will furnish Medicaid state plan day habilitation and case management services within 90-days to all individuals who had sought them in the past. In the case of individuals who newly qualify for services, the agreement provides for their receiving case management and day habilitation services within no more than 225 days. When individuals also qualify for the waiver program and require “residential training services,” the agreement defines “reasonable promptness” as starting services in no more than 18-months. This timeframe reflects the state’s experience about the amount of time it takes to develop a residential setting that matches the needs and preferences of an individual, although state officials note that often less time is required. However, the agreement does not require the state to expand the waiver program over and above the already approved number of slots.

#### **12. Massachusetts: Boulet et al. v. Cellucci et al.**

This class action complaint was filed in March 1999 (originally as Anderson v. Cellucci) by private attorneys on behalf of the plaintiffs and their families who were dissatisfied with the state’s pace in reducing its waiting list. The complaint asserted that Massachusetts violated federal Medicaid law and the ADA by failing to provide residential services with reasonable promptness to otherwise eligible individuals and by wait-listing them indefinitely. While the state had reduced the waiting list, the plaintiffs sought to accelerate the expansion of residential services.

In July 2000, the District Court issued a summary judgment in the plaintiffs’ favor, ruling that the state was required to furnish Medicaid residential services with reasonable promptness. But, the Court certified a narrower class than proposed by the plaintiffs who had asked that it include all individuals wait listed for Medicaid residential services along with persons who would be eligible for them in the future. The Court narrowed the class to individuals already participating in the HCBS waiver program who were wait listed for residential services or wait listed persons not served in the waiver program who could be accommodated under its participant cap. The Court directed the state to furnish residential services to class members within 90-days or, if not feasible, to propose a plan to comply with the reasonable promptness requirement.

In November 2000, the parties agreed in principle to a settlement. In January 2001, the court approved a set-

tlement agreement. The agreement modified the class to include all individuals wait listed as of July 2000, regardless of whether the person was receiving or would be eligible to receive HCB waiver services. The modified class had 2,437 members, including 1,961 waiting for out-of-home residential services only, 266 waiting for both residential and non-residential services (e.g., day services), and 210 waiting for non-residential services only. Under the agreement, the state committed to provide residential services to 300 more individuals in FY 2001 using already appropriated funds. Over the next five years (FY 2002 – 2006), the state agreed to seek funding to provide residential services to an additional 1,975 individuals at a pace of 375 – 400 persons per year. Individuals who do not receive residential services right away would receive “interim services” (in-home, family support and other services) until residential services became available. The parties also agreed to procedures for preparing residential and interim service plans. Over the five-year period 2002 – 2006, the state committed \$355.8 million in total funding to expand services. Since the settlement, each year additional funds have been appropriated in accordance with the agreement.

#### **13. Montana: Travis D. et al. v. Eastmont Human Services Center**

Filed in 1996 by the Montana Advocacy Program (the state’s P&A agency), this complaint alleged that Montana violated federal Medicaid law, the Americans with Disabilities Act integration mandate and the U.S. Constitution by failing to provide community services to residents of the state’s two public MR/DD institutions and individuals in the community at risk of institutionalization.

Court action stalled for a variety of reasons, including off and on settlement negotiations between the parties, the ill-health of the presiding judge, and a one-year stay pending the U.S. Supreme Court’s Olmstead decision. In August 2001, the presiding judge declared all the pending motions moot, deciding that starting over with a fresh set of motions would expedite the case. The parties submitted new briefs in May 2002. The lawsuit was narrowed to a class of an estimated 200 individuals served at Montana’s two public institutions (Eastmont Human Services Center and Montana Developmental Center (MDC)) since August 1996. The remaining claims concerned community integration under the ADA, the Rehabilitation Act, and the U.S. Constitution. Meantime, in its 2003 session, the Montana legislature approved the closure of Eastmont and the Center closed in December 2003.

The parties arrived at a mediated settlement agreement that in February 2004.<sup>22</sup> The agreement provides that the state will move 45 MDC residents into community living arrangements over the next four years. MDC currently serves approximately 90 individuals. The state also agreed to: (a) the repeal of a Montana law that allows court commitment of individuals who have “near total care” requirements. This law has been a leading source of new admissions to state facilities; (b) commit \$200,000 annually for crisis prevention and intervention services to help maintain people in the community and reduce crisis admissions to MDC; (c) make improvements in MDC services; (d) improve its community quality assurance program; and, (e) take additional steps to strengthen community services for individuals with developmental disabilities.

#### **14. Nebraska: Bill M. et al. v. Department of Health and Human Services et al.**

In May 2003, six individuals with developmental disabilities filed suit (03-cv-03189) against the Nebraska Department of Health and Human Services in the U.S. District Court for Nebraska. The lawsuit charges that Nebraska has impermissibly wait listed individuals for waiver services and, furthermore, that the state’s policies result in inadequate services being furnished to a large percentage of waiver participants. The plaintiffs are represented by private attorneys and Nebraska Advocacy Services, the state’s P&A. Class action certification also is sought for:

All present and future individuals with developmental disabilities in Nebraska who are eligible for Medical Assistance Home and Community-Based Services but either are not receiving funding for such services, or are not receiving sufficient funding for such services to reasonably achieve the purpose of the service, assure the class member’s health and safety, or ensure progress toward independence, interdependence, productivity and community integration.

The lawsuit alleged that about 800 individuals were waiting for services in Nebraska. In addition to seeking services for these individuals, the lawsuit challenges the state’s methods for authorizing services under its program. The state uses assessment results to set the number of hours of services a person may receive. The plaintiffs contend that this method is flawed because it leads to a large but unknown percentage of individuals not receiving enough hours of services to meet essential health and safety needs and/or make progress in achieving their individual goals.

The plaintiffs claim that the state violates: (a) the ADA and §504 of the Rehabilitation Act because the waiting list does not move at a reasonable pace and Nebraska does not have an effective working plan as called for in the Olmstead decision; (b) §1902(a)(8) of the Act by denying individuals the opportunity to apply for the waiver program and not providing services with reasonable promptness; (c) §1902(a)(10)(B) because the state’s service authorization mechanism impermissibly restricts the amount, duration and scope of services; (d) §1915(c)(2)(A) because the mechanism does not assure the health and welfare of waiver participants [N.B., The plaintiffs also allege that the state violates the requirements spelled out in CMS Olmstead Letter #4]; (e) Nebraska state law and regulations that require assisting individuals to achieve critical life outcomes; and, (f) the U.S. and Nebraska Constitutions and federal Medicaid law by not providing adequate due process protections and the right to a Medicaid Fair Hearing.

By way of relief, the plaintiffs want the court to direct the state to prepare and implement a comprehensive effective working plan that moves the waiting list at a reasonable pace, immediately provide waiver services to eligible individuals up to the number of waiver slots presently available, expand the program to serve more persons over the next three years, and revamp its service authorization mechanism.

In July 2003, the state moved to dismiss the ADA and §504 claims. The state argued that it enjoys sovereign immunity protection against lawsuits brought under the ADA and has not discriminated against individuals under either the ADA or §504. Furthermore, it asserted that the ADA, §504 and the Olmstead decision do not require a state to increase its spending for community services. Since none of the defendants are institutionalized, the state argued that they cannot make Olmstead-related claims.

In August 2003, the plaintiffs replied to the state’s motion to dismiss. They argued that, by accepting federal Medicaid funds, the state waived sovereign immunity. They also disputed the state’s interpretation of the Olmstead decision on several grounds, including the state’s assertion that it applies only to institutionalized persons. The plaintiffs also filed an amended complaint.

In October 2003, the state filed another motion to dismiss. The state reiterated its arguments concerning the ADA and §504 claims and again asserted sovereign immunity. In addition, the state contended that plaintiffs’ grievances were more properly addressed through state administrative appeals processes, which are subject to state judicial review. The state also

<sup>22</sup> The settlement agreement and related materials are located on Montana Advocacy Program website at: [www.mntadv.org/](http://www.mntadv.org/).

disputed the validity of plaintiffs' claims under federal Medicaid law. Finally, the state argued that claims based on Nebraska state law are outside the jurisdiction of federal courts in litigation brought under the provisions of §1983.

In early November 2003, the plaintiffs replied to the state's motion to dismiss, disputing each of the state's arguments. Later in the month, the state filed its reply brief, reasserting its arguments in support of dismissal.

In July 2004, the plaintiffs filed the motion for class certification. The plaintiffs estimate that the class now includes 1,400 individuals who waited for services for more than 90 days and 2,200 persons who are receiving inadequate community services or at risk of having their services reduced.

In August 2004, the court denied the state's motion to dismiss the ADA claim on sovereign immunity grounds. In September 2004, the state appealed this decision to the 8<sup>th</sup> Circuit Court of Appeals (04-3263). The district court suspended further proceedings until the 8<sup>th</sup> Circuit ruled on the appeal.

In May 2005, the Circuit Court agreed with the state and ordered the district court to dismiss the ADA claim, finding that Congress did not abrogate the state's sovereign immunity under Title II of the ADA.<sup>23</sup> The plaintiffs sought en banc review of the decision but this request was denied in August 2005.

In September 2005, the district court accepted a magistrate judge's recommendation to deny class certification. The magistrate judge found that the proposed class was too diverse and amorphous to meet federal court requirements for certification.

#### **15. New Hampshire: Cuming et al. v. Shaheen et al.**

In January 2002, the Disabilities Rights Center (the state's P&A agency) filed a class action complaint in Hillsborough County Superior Court, arguing that New Hampshire failed to provide adequate community-based services for people with developmental disabilities. The suit alleged that there are "well over 500 individuals" in the proposed class, including 325 Medicaid-eligible individuals wait-listed for services and a large number of persons who receive inadequate or inappropriate services. The plaintiffs demanded that the state furnish a "comprehensive array" of individualized community services.

The suit charged the state has not developed an adequate system of community services and programs, "including sufficient numbers of ICF/MR and other

community living arrangements that meet the individualized needs of persons with developmental disabilities..." The suit asked the court to order the state to furnish improved services not only for the wait listed persons but also for individuals who receive services but have been "...left to languish in inappropriate and, sometimes, overly restrictive placements." The plaintiffs expressed dissatisfaction with the state's attempts to develop programs and services for this group, portraying such efforts "piece-meal and inadequate."

This lawsuit suit was filed in state rather than federal court and relies both on state and federal law as its basis. In particular, the suit claims that the state is violating: (a) New Hampshire law (RSA 171-A:13) which provides that "every developmentally disabled client has a right to adequate and humane habilitation and treatment including psychological, medical, vocational, social, educational or rehabilitative services as his condition requires to bring about an improvement in condition within the limits of modern knowledge"; (b) §1902(a)(8) of the Act for waiting listing otherwise eligible persons and §1902(a)(3) for failing to provide a Fair Hearing for individuals whose claim for Medicaid services has not been acted upon with reasonable promptness; (c) Title II of the ADA for not having developed a sufficiently comprehensive program so that all persons with developmental disabilities can "remain in the community with their family and friends," thereby putting them "at risk of being provided with inadequate, inappropriate or overly restrictive programs and services"; (d) the 5<sup>th</sup> and 14<sup>th</sup> Amendments to Constitution and 42 U.S.C. §1983 for abridging the plaintiffs' due process rights; and, (e) the 14<sup>th</sup> Amendment for violating individuals' right to equal protection by serving some individuals but wait-listing others.

In April 2002, the court denied the plaintiffs' petition for injunctive and declaratory relief. The plaintiffs' petition included six requests that covered class certification and called for the state to offer all eligible plaintiffs community services within 90 days. The court concluded that the petition did not meet New Hampshire's tests for such relief. Deciding that the "proposed class members' claims... include claims that extend far beyond those of the named plaintiffs," the court also denied class certification.

In a subsequent proceeding, the court reversed itself concerning class certification. But, then in March 2003, the court again decided to deny certification, ruling that the proposed class was too broad and likely included individuals whose service needs were different and therefore might have different interests.

<sup>23</sup> The opinion and the briefs filed in the appeal are located at: [ca8.uscourts.gov/tmp/043263.html](http://ca8.uscourts.gov/tmp/043263.html)

The plaintiffs appealed the denial of class certification to the New Hampshire Supreme Court, which refused to hear the appeal. The parties then agreed that the lawsuit would be treated as a voluntary non-suit without prejudice (i.e., the plaintiffs are free to refile later) and the case was dismissed (Priault, 2004).

#### **16. New Mexico: Lewis et al. v. New Mexico Department of Health et al.**

This lawsuit (99-00021) was filed in January 1999 in the U.S. District Court for New Mexico by the state's P&A agency with the support of The Arc of New Mexico. The class action complaint alleged New Mexico violated federal Medicaid law and the ADA by failing to provide Medicaid services in the community to eligible individuals with disabilities, thereby causing them to go without services or forcing them to accept institutional services. The proposed class included: (a) people with developmental disabilities wait-listed for HCB waiver services; (b) persons served in ICFs/MR who would benefit from waiver services; (c) persons served in nursing facilities who want community services; and, (d) wait-listed persons with disabilities who seek access to the state's waiver for persons who are aged or disabled.

In April 2000, the court rejected the state's motion to dismiss the lawsuit on sovereign immunity grounds and upheld the plaintiffs' right to access to waiver services with "reasonable promptness." In May 2000, the state asked the 10<sup>th</sup> U.S. Circuit Court of Appeals to reconsider of its immunity claim. Under federal judicial rules, an appeal based on a sovereign immunity claim stays further lower court action until the appeal is decided. Finally, in August 2001, the 10<sup>th</sup> Circuit denied the state's appeal.<sup>24</sup>

In September 2001, the state moved again to dismiss the complaint, arguing that the lawsuit was moot because all the original named plaintiffs either were receiving waiver services or deceased. The state also challenged the P&A's standing to pursue this litigation in its own right. In November 2001, the P&A filed a counter brief, arguing that it had standing under federal law to pursue the lawsuit and filed a motion to amend the original complaint.

In July 2002, the plaintiffs moved for summary judgment, contending that the "case presents a simple, straight forward question of law: Are the Defendants required to provide Medicaid waiver services to all eligible individuals with reasonable promptness? The law is clear and unequivocal: the defendants are so required." In support, the plaintiffs pointed out that 2,600 individuals were wait listed for the state's HCBS

waiver program for people with developmental disabilities. The program served 2,300 individuals and has a federally approved cap of 3,200. There were 2,500 persons wait listed for the state's HCBS waiver program for individuals who are disabled or elderly; that program served 1,500 individuals or 450 fewer than the federally-approved "cap." The plaintiffs also noted that the average period that persons with developmental disabilities must wait for services was worsening and might reach 60-months. The plaintiffs argued that these facts were ample evidence that New Mexico did not furnish waiver services with reasonable promptness. The plaintiffs also took the state to task for not properly taking applications for waiver services. Instead, individuals are assigned to a "Central Registry" and eligibility is only determined once their name comes up. The state portrayed individuals on the Registry as having "applied to be considered" for waiver services rather than actual applicants. The plaintiffs argued this practice violates Medicaid law.

In August 2003, the court granted the plaintiffs' motion for summary judgment, ruling that the state had not furnished waiver services with reasonable promptness. However, the court decided that the Medicaid reasonable promptness requirement extends only so far as there are funds and waiver slots available but not beyond such limits. Thus, the court's ruling did not require that the state expand its program to serve all people on the waiting list. The court noted that the state had in the past not made full use of all available funds and admonished it to step up its efforts to diligently deploy its resources to serve as many individuals as possible each year.

The plaintiffs submitted a proposed order to implement the ruling. In October 2003, the state challenged the proposed order, which asked that the court to enter a permanent injunction to require that the state comply with applicable federal laws. The state argued that its policies met the parameters that the court spelled out in its August 2003 ruling. The state also contended that the proposed order went beyond the court's ruling because it would require the state to serve more people in its waiver programs than the funds appropriated by the legislature. The state counter proposed that the court enter judgment in its favor.

In November 2003, the plaintiffs replied that the state had misconstrued the court's August 2003 order. They asserted that the order provided that: (a) the state must promptly determine the eligibility of applicants rather than entering their names into a registry for future consideration when waiver slots become available and (b) the state must serve all eligible individuals until it

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<sup>24</sup> Decision is at: [laws.findlaw.com/10th/002154.html](http://laws.findlaw.com/10th/002154.html)

reaches its federally-approved participant cap, irrespective of whether the legislature has earmarked the necessary dollars.

In February 2004, the court entered its judgment. The court ordered the state to allocate waiver slots as soon as they become available and determine an individual's eligibility for waiver services within 90 days. It also ordered that the state provide waiver services within 90-days of finding that a person is eligible for waiver services. It also ordered the state to spend all funds appropriated for waiver services within the year appropriated. New Mexico advocates expected that 300 – 500 individuals will come off the waiting list as a result of this decision.

In September 2004, the plaintiffs filed a motion for the court to hold the state in contempt. The plaintiffs argue that the state is violating the court's order to offer waiver services up to the federally approved participant limit for each waiver program. In October 2004, the state responded, arguing that the plaintiffs misunderstood the court's February ruling and that the state's obligation to furnish waiver services goes only so far as the funds it has available, not the waiver participant limit. The state urged the court to dismiss the plaintiff's new motion. Finally, in September 2005, the court denied the plaintiffs' motion for contempt, ruling that New Mexico was obligated to furnish waiver services only to the extent supported by available funds.

#### **17. Ohio: Martin et al. v. Taft et al.**

Filed by Ohio Legal Rights Services (OLRS - the state's P&A agency) in 1989, this class action complaint (89cv0362) alleges that Ohio violates Medicaid law as well as the ADA by failing to provide integrated residential services to all persons with developmental disabilities eligible for them. In 1993 the court rejected the state's motion to dismiss the ADA claim on the basis of an 11<sup>th</sup> Amendment sovereign immunity defense, holding that Congress, in this instance, had the authority to abrogate immunity. In 1998, the parties agreed to a motion to stay further district court proceedings in the hope of working out an agreement to expand services. However, in July 2000, OLRS filed a motion for partial summary judgment asking the Court to find that the state is violating the ADA integration mandate because its Medicaid waiver waiting list is not "moving at a reasonable pace."

In September 2002, the Court ruled on various motions. The Court denied the state's motion to dismiss on sovereign immunity grounds and upheld some of the plaintiffs' claims. However, the Court turned down the plaintiff motion for partial summary judgment.

The Court urged the parties to settle the lawsuit, which had dragged on for more than a decade.

In June 2004, the parties announced that they had arrived at a settlement agreement. The class affected by this agreement included: "[A]ll mentally retarded or developmentally disabled Ohioans who are, or will be, in need of community housing and services which are normalized, home-like and integrated, and a subclass who, in addition to being members of the class, are or will be, Medicaid recipients." The agreement focused on providing community-integrated services to individuals who reside in state-operated residential centers, nursing homes, and large ICFs/MR.

Under the terms of the agreement, Governor Taft, in his FY 2006 and FY 2007 executive budget, agreed to propose "... the elimination of intermediate care facilities for the mentally retarded under the State of Ohio's Medicaid [state] plan." If the legislature approves legislation authorizing this action, the state then will submit a waiver request to the U.S. Department of Health and Human Services that would afford all ICF/MR residents the right to choose the setting in which they receive services. The agreement also provided that the state would earmark waiver slots to support the community transition of ICF/MR and nursing facility residents with developmental disabilities. The state also agreed to survey state developmental center and ICF/MR residents to determine the number who want to transition to the community. A fairness hearing was scheduled for September 2004.

The proposed settlement unleashed a torrent of protest. Dozens of objections to the settlement were filed with the court over the summer. The objections to the settlement revolve around the proposed elimination of ICF/MR services from the Ohio Medicaid program. The objectors, many of whom are ICF/MR residents and their guardians, believe that this step will undermine their entitlement to these services under federal law. The objectors petitioned the court to decertify the class, arguing that the agreement and the plaintiff attorneys do not adequately represent their interests. The high volume of objections led the court to cancel the fairness hearing. In response, the state and the plaintiffs filed "points of clarification" concerning the agreement and, in October 2004 filed a memorandum in opposition to dissolving the class. The state and the plaintiffs contended that the settlement maintains the ability of individuals to continue to reside in their current living arrangements but would clear the way for Ohio to come into compliance with the ADA's integration mandate.

Additional plaintiff objectors have filed motions to dissolve the class. The controversy concerning the proposed settlement has continued to grow. In December 2004, Governor Taft announced that the state was withdrawing its objections to decertifying the class. If the class is dissolved, the proposed settlement would be nullified. The Taft Administration expressed the view that the policy changes incorporated in the settlement agreement are more properly addressed in the legislative arena.

In mid-February 2005, the court – over the objections of the ever-growing number of parties – appointed a Special Master to attempt to broker a new settlement agreement. However, no progress has been along these lines. In September 2005, the Special Master recommended that the court not dissolve the class. This recommendation triggered responses from the objectors that the court dissolve the class.

#### **18. Oregon: Staley et al. v Kulongoski et al.**

Filed in January 2000, this complaint (00cv00078) alleged that the state violated federal Medicaid law and the ADA by failing to furnish Medicaid long-term services to otherwise eligible individuals with developmental disabilities with reasonable promptness. In September 2000, the parties agreed to settle the lawsuit. The U.S. District Court for Oregon approved the settlement agreement in December 2000.

The settlement agreement was designed to implement the Universal Access Plan. The Plan provided that all eligible adults would receive at least a basic level of supports. The parties agreed that the settlement would include not only the named plaintiffs but also “all other similarly-situated individuals with developmental disabilities under the federal Medicaid program.” The settlement extended to 2007 and provided that the state would increase community funding by a cumulative total of \$350 million. Under the agreement, the number of persons receiving “comprehensive services” (including 24-hour residential services) would grow by 50 per year over and above the number of individuals who receive such services due to emergencies. The state also agreed to furnish comprehensive services to all individuals in crisis. The number of persons receiving “support services” (defined as “in-home and personal supports costing up to \$20,000 per year”) would increase by 4,600 over the agreement’s six-year period. Also, the agreement called for making additional investments in system infrastructure.

In its 2001 session, the Oregon Legislature funded the first two-years of the settlement. Also, to implement the plan, Oregon launched a new “self-directed support services” waiver program. But, Oregon experienced a

steep drop in state revenues, leading to deep cuts in spending. In August 2002, the Oregon Advocacy Center (the state’s P&A agency) warned that it was prepared to return to court to seek relief under the material breach provisions of the settlement if budget cut-backs led the state not to fund the agreement. In February 2003, the state imposed a moratorium on enrollments in its waiver programs. By then, about 3,000 individuals were participating in the supports waiver.

In October 2003, the parties presented a modified settlement agreement to the court. The modified agreement acknowledged that Oregon’s severe budget crisis meant that the agreement’s timetable could not be followed. Under the modified agreement,<sup>25</sup> the state was given until 2011 to fully implement the original agreement. The pace of expansion of both comprehensive and support services was slowed but the agreement still provides that in the end all eligible individuals would receive at least support services. The modified agreement provides for an additional 500 persons to receive support services each year through June 2007, when the number of persons served is expected to reach 5,122 individuals compared to 3,112 in June 2003. The agreement provides that all eligible persons will receive support services by June 2009. The modified agreement also preserves the network of support brokerages that Oregon created for individuals who receive support services. The parties agreed that the modified settlement was preferable to re-opening the litigation. In January 2004, the court gave its approval to the modified agreement because the affected class members raised no objections.

#### **19. Pennsylvania: Sabree et al. v. Richman**

In May 2002, the Disability Law Project and two private attorneys filed a class action complaint (02-CV-03426) in the U.S. District Court for Eastern Pennsylvania against the Department of Public Welfare on behalf of four individuals who contend that the state had improperly wait listed them for ICF/MR services. The complaint was filed in reaction to a proposed reduction of the dollars committed to reducing Pennsylvania’s community waiting list. The lawsuit is sponsored by the Pennsylvania Community Advocacy Coalition.

The plaintiffs’ Sabree complaint was brief. It argued that Pennsylvania has not furnished ICF/MR services as required under its Medicaid state plan to eligible individuals with reasonable promptness, in violation of

<sup>25</sup> Information concerning the modified settlement agreement as available on the Oregon Advocacy Center’s website: [www.oradvocacy.org/staley2003.htm](http://www.oradvocacy.org/staley2003.htm).

§1902(a)(10)(A) (by not making entitled ICF/MR services available to all eligible persons) and §1902(a)(8) of the Act. The plaintiffs sought class action certification. The proposed class would include “all Pennsylvanians with mental retardation living in the community who are entitled to, in need of, but not receiving appropriate residential and habilitative programs under the Medical Assistance program.”

The state filed moved to dismiss the complaint and opposed to class certification. The state argued that the complaint did not satisfy the test for bringing a lawsuit under §1983 because there is no federally enforceable individual right to ICF/MR services in small community residences and the reasonable promptness requirement applies in the “aggregate” but not to individuals. In July 2002, the plaintiffs urged the Court to deny the motion to dismiss, arguing that ICF/MR services are an individual entitlement under federal law and citing several federal court decisions that declared reasonable promptness is an enforceable individual right. The plaintiffs also argued that Congress had affirmed the enforceability of these rights.

In January 2003, the district court dismissed the lawsuit, accepting the state’s arguments. The court based its dismissal on: (a) its view that Medicaid law does not confer an individually enforceable right to services and, hence, the action does not meet the criteria for bringing a lawsuit under §1983. The court ruled that the Medicaid Act has an “aggregate” focus (e.g., whether the state is following its overall plan) rather an “individual focus;” (b) the availability of a mechanism for individuals to appeal adverse decisions (the Fair Hearing process) means that an action cannot be brought under §1983, based on the Supreme Court’s *Gonzaga* decision; and, (c) in any case, the court found that federal Medicaid law does not require that a state furnish ICF/MR services in small community group homes, and, thus, the plaintiffs cannot assert a right to such services. The court concluded that the “individuals referenced [in the lawsuit] are merely beneficiaries, not persons entitled to privately enforce the statute.” The court also concluded that only the federal government could sue the state over the operation of its Medicaid program.

In January 2003, the plaintiffs appealed the dismissal to the 3<sup>rd</sup> Circuit Court (03-1226). Ilene Shane, director of the Disabilities Law Project said, “We’re appealing because we believe it’s not a correct decision. If this decision were to be followed, it would reverse 30 years of jurisprudence where people with disabilities have litigated their rights.” Several organizations filed amicus briefs in support of the appeal, including AARP, Arc US, Families USA, and others.

In May 2004, the Circuit Court handed down a “precedential” opinion in this appeal.<sup>26</sup> In a nutshell, the Circuit Court reversed the district court ruling. The Circuit ruled that – the *Gonzaga* decision notwithstanding – federal Medicaid law conferred individually enforceable rights under the Social Security Act provisions that were the basis of the lawsuit’s legal claims.

In November 2004, the plaintiffs filed an amended complaint in district court, reasserting their right to receive ICF/MR services with reasonable promptness. In September 2005, the plaintiffs moved that the court dismiss the lawsuit because a settlement agreement had been worked out with the three named plaintiffs. The court accepted this motion.

**20. Tennessee: Brown et al. v. The Tennessee Department of Mental Health and Developmental Disabilities and Rukeyser & People First of Tennessee v. Neal et al.**

**Brown.** Filed in July 2000 by the state’s P&A agency, this class action complaint (00cv00665) alleges that Tennessee has violated federal Medicaid law by not furnishing ICF/MR or HCB waiver services with reasonable promptness to otherwise eligible individuals with developmental disabilities. The complaint estimated that about 850 individuals were wait listed for waiver services.

**People First.** In March 2001, People First of Tennessee filed another class action complaint (01cv00272), also in the U.S. District Court for Middle Tennessee. This complaint asserts that the state: (a) has failed to provide ICF/MR or HCB waiver services with reasonable promptness; (b) violates the ADA by failing to make reasonable modifications and accommodations so that individuals (including institutionalized persons) are served in the most integrated setting; (c) does not comply with §1902(a)(10) of the Act since it has not made ICF/MR or waiver services available to all eligible persons; (d) has denied individuals the right to apply for or be made aware of Medicaid services; (e) has discriminated against people with disabilities by not permitting all otherwise eligible persons to obtain services for which they are entitled, in violation of the ADA; (f) violates §1902(a)(3) of the Act and the Due Process Clause of the U.S. Constitution’s 14<sup>th</sup> Amendment by not providing individuals written notice of denial of Medicaid services, thereby preventing them from exercising their appeal rights; (g) has denied individuals free choice in receiving HCB waiver or ICF/MR services; and, (h) violates the Individuals with Disabilities Education Act by denying

<sup>26</sup> The opinion is at: [ca3.uscourts.gov/opinarch/031226p.pdf](http://ca3.uscourts.gov/opinarch/031226p.pdf)

Medicaid payment for services to which school-age children are entitled.

The complaint alleged that approximately 2,000 persons with developmental disabilities were waiting for waiver services in Tennessee. The plaintiffs contend that the state has given insufficient attention to a growing backlog of people who need community services because most new resources are committed to placing residents out of state-operated institutions to comply with court orders in earlier institutional treatment lawsuits (People First v. Clover Bottom, et. al and United States of America v. State of Tennessee).

**Status.** In May 2003, the presiding judge asked the parties to consider consolidating both cases. The court arranged for a mediator and halted further activity pending the outcome of mediation. The court also denied both sets of plaintiffs' and the state's motions for summary judgment.

In February 2004, the Court gave its provisional approval to separate settlement agreements in both cases. These agreements are described below. A fairness hearing was held in April 2004 to hear objections to the agreements. In June 2004, the Court gave its final approval to the agreements.

**Brown Settlement.** Under the terms of this agreement, the state has agreed to formulate and seek federal approval of a new Self-Determination HCBS waiver program to serve individuals wait listed for services. The aim of the agreement is to eliminate or substantially reduce the waiting list. The new waiver program would provide up to \$30,000 in services to each person and designed to give individuals (or, their families, if appropriate) latitude in selecting and directing their services. This funding is to be supplemented, if necessary, by additional short-term crisis and/or one-time diversion dollars to provide temporary additional services. The agreement provides that the new program would serve 600 individuals in its first year of operation and an additional 900 persons in the second year. Beyond the second year, the parties will reach agreement concerning further expansion of the program to address unmet needs. The agreement directs the state to offer services through the new waiver program on a priority basis to individuals who are in crisis or have urgent needs. In the event that a person's needs cannot be met through the self-determination waiver, the individual will have the option to choose services through another waiver program.

The agreement also provides for the further expansion of the state's current HCBS waiver program. Moreover, persons who remain on the waiting list are to receive \$2,280 per year in "consumer-directed support" funding. The agreement also commits the state to

implementing a Medicaid targeted case management program to specifically support individuals on the waiting list. The agreement provides for additional improvements in community services infrastructure.<sup>27</sup>

**People First Settlement.** This settlement agreement acknowledges and complements the Brown settlement. The focus of this agreement is to "assure that all Tennessee citizens who might be eligible for waiver services are given a reasonable opportunity to learn of the availability of waiver services and to apply for them." The state has agreed to conduct a public information campaign to provide information to individuals who might be Medicaid-eligible regarding the waiver programs. The state also is to compile information concerning the number of individuals with mental retardation who are eligible for Medicaid waiver services but not receiving them.

### 21. Texas: McCarthy et al. v. Hawkins et al.

In September 2002, eleven individuals and The Arc of Texas filed a class action complaint in the United States District Court for Eastern Texas against the Commissioners of the Texas Health and Human Services Commission (THHSC), the Texas Department of Mental Health and Mental Retardation (TDMHMR) and the Texas Department of Human Services (TDHS). The complaint charges that Texas has failed to "provide the plaintiffs and other Texans with mental retardation and developmental disabilities with community-based living options and services to which they are legally entitled that meet their needs." The lawsuit asks the court to direct Texas to expand Medicaid home and community-based waiver services.

By way of background, THHSC is the Texas Medicaid Agency; TDMHMR operates the state's Medicaid home and community-based services (HCS) waiver program for persons with mental retardation; TDHS operates the Community Living Assistance and Support Services (CLASS) Medicaid waiver program for persons with developmental disabilities other than mental retardation. Advocacy Inc., the state's P&A agency, filed the complaint.

The complaint charges that about 17,500 people with mental retardation are wait listed for the HCS waiver program (which presently serves about 4,600 individuals) and another 7,300 individuals have requested but not received CLASS waiver services (the program serves about 1,800 individuals). The plaintiffs seek certification of a class that would include "all persons eligible to receive Medicaid waiver services, who have requested but not received waiver services with

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<sup>27</sup> For information about what has transpired since the settlement was approved, go to: [tpainc.org/content.asp?contentid=41](http://tpainc.org/content.asp?contentid=41)

reasonable promptness.” The class also would include 11,000 individuals served in ICFs/MR who “are eligible to be considered for the kind of residential services that will enable them [to] become more fully integrated into the community.” This class is the largest proposed in a waiting list lawsuit to date.

The complaint charges that the state is violating: (a) §1902(a)(10)(A) of the Act by failing to make ICF/MR level services available in an adequate amount, duration and scope to all eligible persons; (b) §1915(c)(2)(C) by failing to provide individuals a choice between institutional and home and community-based services; (c) §1902(a)(8) by (i) not allowing individuals to apply for waiver services and instead wait listing them and (ii) not furnishing services to eligible individuals with reasonable promptness; (d) the 14<sup>th</sup> Amendment to the U.S. Constitution by not affording individuals equal protection; (e) the Due Process Clause of the U.S. Constitution; (f) the ADA and §504 of the Rehabilitation Act by failing to provide services in the most integrated setting. The state filed a motion to dismiss. In March 2003, the court granted the state’s motion to transfer the lawsuit to the Western District of Texas. (03-CV-231)

In May 2003, the Western District court issued an order that addressed eleven motions filed by both sides. First, the court denied the state’s motion to dismiss The Arc of Texas as a plaintiff in the litigation. The court, however, granted the state’s motions to dismiss the plaintiffs’ claims with respect to most provisions of Medicaid law, including comparability, HCBS waiver program freedom of choice, and reasonable promptness. With respect to these claims, the court held that states were authorized to limit the number of persons who participate in a waiver program and, thus, individuals cannot assert an enforceable right to such services once the waiver participant limit had been reached. But, the court turned down the state’s motion to dismiss the plaintiffs’ claims concerning due process under Medicaid law and the U.S. Constitution as well as the ADA and §504 claims. The court found that, with respect to these claims, the plaintiffs had individually enforceable rights and, hence, could seek redress in federal court under the provisions of §1983. In this part of the decision, the court relied heavily on the Olmstead decision, although it noted that the fundamental alteration defense might stand as a substantial barrier to the plaintiffs’ ultimately prevailing. The court also turned down the state’s sovereign immunity claims.

In June 2003, the state appealed the parts of the decision that ran against it to the 5<sup>th</sup> Circuit Court of Appeals (03-50608), once again claiming that sov-

eign immunity insulates the state from lawsuits based on the ADA and §504. As a result, district court proceedings were stayed until the Circuit disposed of the state’s interlocutory appeal. The Circuit allowed the U.S. Department of Justice to intervene on behalf of the plaintiffs. In its brief,<sup>28</sup> USDOJ urged the court to turn down the appeal, arguing that it is well-established that states may be sued in federal court for alleged violations of both the ADA and §504. A coalition of national organizations, including ADAPT, The Arc of the United States, the American Association of People with Disabilities and others, also petitioned the court to file *amici* brief on behalf of the plaintiffs. The court heard oral arguments in April 2004.

In August 2004, the three-judge panel handed down a split 2-1 decision. This decision solely addressed the relatively narrow issue of whether state officers are proper defendants in a lawsuit brought under Title II of the ADA.<sup>29</sup> Texas had argued that only public entities could be sued under Title II. The panel ruled that state officers could be sued in their official capacity, a ruling that is consistent with similar rulings in other cases. The panel refused to hear the state’s arguments to dismiss the remaining claims, because such issues were not proper subjects for interlocutory appeal. In September 2004, the state petitioned for the appeal to be heard *en banc* by the full Circuit Court. In December 2004, this petition was denied and the case remanded to the district court for further action. The state considered but decided against pursuing an appeal of the Circuit Court decision to the U.S. Supreme Court. The lawsuit will now go to trial.

## 22. Utah: D.C. et al. v. Williams et al.

In December 2002, the Utah Disability Law Center (the state’s P&A) filed suit (02cv01395) against the Utah Department of Health and the Division of Services for People with Disabilities in the U.S. District Court for Utah on behalf of nine individuals and the Arc of Utah challenging the wait listing of persons with developmental disabilities for waiver services. The plaintiffs argue that wait listing violates federal Medicaid law, the ADA, and §504. Class certification is sought for roughly 1,300 individuals who have been found to have an immediate need for services but have been wait listed.

Plaintiffs contend that the state has: (a) refused to pro-

<sup>28</sup> The brief is at: [usdoj.gov/crt/briefs/mccarthy.pdf](http://usdoj.gov/crt/briefs/mccarthy.pdf).

<sup>29</sup> Opinion is at: [caselaw.lp.findlaw.com/data2/circs/5th/0350608pv2.pdf](http://caselaw.lp.findlaw.com/data2/circs/5th/0350608pv2.pdf). For a discussion of this decision, go to: [healthlaw.org/pubs/courtwatch/200409.fifthcircuit.html](http://healthlaw.org/pubs/courtwatch/200409.fifthcircuit.html)

vide medically necessary waiver services to individuals; (b) failed to operate its Medicaid program in the best interest of recipients, as required in §1902(a)(19) of the Act; (c) not operated its Medicaid program to assure that services are sufficient in amount, scope and duration; (d) violated §1915(c)(2)(C) by not making waiver services available to individuals who qualify for ICF/MR services; (e) violated §1902(a)(8) of the Act by not making services available with reasonable promptness; (f) violated the ADA's integration mandate by placing individuals at risk of institutionalization; and, (g) violated §504 of the Rehabilitation Act. The plaintiffs seek declaratory and injunctive relief in the form of an order that the state to develop a plan to serve wait listed individuals.

In January 2003, the state moved to dismiss the complaint, contending that:

"[the] plaintiffs lack standing because they have no protected right to HCBS waiver services. Specifically, plaintiffs possess no protected right to HCBS waiver services because of the upper limit [on the number of participants] and other Medicaid limitations placed on HCBS waiver services, and the substantial discretion granted [the state] in administering and providing HCBS waiver services."

The state argued that, because federal law allows it to limit the number of individuals served in its waiver program, people wait-listed for the waiver cannot have an enforceable right to waiver services. Since they lack such a right, the state contended that the reasonable promptness requirement does not apply. Also, absent a right to waiver services, the state argued that plaintiffs do not have standing to bring suit under §1983. With respect to the plaintiffs' claim that the state is violating §1915(c)(2)(C) by not giving individuals eligible for ICF/MR services a choice of waiver services, the state argued that it is only obligated to inform individuals of "feasible alternatives, if available under the waiver." If services are not available, then a "feasible alternative" does not exist. The state also asserted that the Supreme Court's Olmstead ruling does not apply because "plaintiffs are not being held in institutional placements against their will, [and hence] the ADA and Rehabilitation Act are inapplicable." Lastly, the state argued that, in order to serve all wait-listed individuals, it would be forced to make a "fundamental alteration" by having to shift funds away from other programs in order to meet the needs of the plaintiffs. The state pointed out that ADA regulations as well as the Olmstead decision "allows states to resist modifications that entail a 'fundamental alteration' of the state's services and programs."

In March 2003, the plaintiffs filed a memorandum opposing the motion to dismiss. They contended that the HCBS waiver program is no different than any other Medicaid service and, therefore, the state cannot waitlist individuals. The plaintiffs also disputed the state's Olmstead interpretation, pointing out that other courts had found that the integration mandate applies to both individuals who are institutionalized and persons at risk of institutionalization.

In August 2003, the court addressed the pending motions. It decided to grant class certification. However, the court threw out the plaintiffs' Medicaid claims, following the district court's reasoning in the Pennsylvania Sabree lawsuit that the Medicaid Act does not grant individually-enforceable rights based on the Supreme Court's Gonzaga decision. The court then took up the state's motion to dismiss the ADA and §504 Rehabilitation Act claims. It rejected the state's argument that such claims may only be pursued by institutionalized persons and denied the motion to dismiss the claims. It also rejected the state's sovereign immunity defense. Trial probably will commence in January 2006.

### 23. Virginia: Quibuyen v. Allen and Smith

Filed in December 2000 in the U.S. District Court for Virginia by a coalition of attorneys, this complaint alleged that the state impermissibly wait-listed individuals already enrolled in the state's HCBS waiver program rather than furnishing the additional services that they required including residential services. The complaint argued that Virginia imposed limits on services to waiver participants that "...are foreign to the statutory and regulatory Medicaid scheme, and indeed are inimical to it in that they establish additional unapproved barriers for otherwise eligible persons to obtain assistance to which they are entitled under federal law." Especially at issue was a June 1999 directive by the Department of Medical Services that restricted the circumstances when additional services (including residential services) would be provided. The directive limited new or expanded services only when a person no longer can remain in the family home due to caregiver incapacity or other critical situations. The complaint argued that this and other policies led to impermissible wait listing of persons for services for which they were otherwise eligible. In September 2001, the state agreed to change its policies so that individuals would receive all the services that they have been determined to require. As a result, the plaintiffs agreed to dismiss the lawsuit.

#### 24. Washington: The Arc of Washington State et al. v. Lyle Quasim et al. & Boyle et al. v. Braddock

**The Arc of Washington State.** Filed in November 1999 in the U.S. District Court for Western Washington, this class action complaint (99cv5577) charged that Washington violated Medicaid law and the ADA by failing to provide long-term services with reasonable promptness to persons with developmental disabilities. The complaint alleged that there are several thousand individuals with developmental disabilities in need of Medicaid funded services but not receiving them and current Medicaid recipients who could benefit from additional services.

In rulings in this lawsuit, the court decided that: (a) eligibility for ICF/MR services is not sufficient to establish an entitlement to waiver services but (b) Medicaid law requires services to be furnished with reasonable promptness. In December 2000, the Court granted the state's motion for summary judgment to dismiss the plaintiffs' ADA claims. The plaintiffs claimed that the ADA requires that, if a state makes waiver services available to some individuals, it must furnish services to all similarly situated individuals. The Court ruled that the ADA cannot serve as the basis for ordering a state to increase the number of individuals who receive waiver services because such an order would constitute a "fundamental alteration."

In April 2001, the parties reached a settlement and submitted it to the court in August. The agreement hinged on action by the Washington legislature to authorize \$14 million in funding to expand services in FY 2003 and annualize these dollars to \$24 million in future years. The legislature approved the first installment. The agreement also called for the parties to identify additional dollars to serve more individuals in the next biennium. Some 1,800 individuals were expected to benefit from the agreement.

But, in December 2002, the court rejected the settlement agreement. Washington Protection and Advocacy Services (WPAS, which represents institutionalized individuals in two other lawsuits) and Columbia Legal Services (which represents individuals in the Boyle v. Braddock litigation described below) objected to the settlement. Both parties argued that the agreement did not assure that the class members (including individuals they represent) would receive the services that they require. The court was persuaded by these arguments and expressed additional reservations about the settlement. As a result, the court rejected the settlement, dissolved the class, and lifted its stay on proceedings.

In June 2003, the court dismissed the lawsuit entirely, following much the same reasoning upon which it dismissed the Boyle lawsuit. The court decided that The Arc of Washington State did not have standing to bring the lawsuit. In moving for dismissal, the state argued that the case was no longer "ripe" for decision because the state was in the process of changing its waiver program. The court accepted this argument. Next, as it had in dismissing the Boyle lawsuit (see below), the court decided that the plaintiffs had not exhausted their administrative remedies. Finally, the court ruled that its intervening into how the state administers its programs would cause "needless conflict with the state's administration of its own regulatory scheme."

In July 2003, the Arc of Washington appealed the dismissal to the 9<sup>th</sup> Circuit (03-35605). In July 2004, the state moved that the Circuit dismiss the appeal. This case was consolidated with Boyle for purposes of oral argument. In March 2005, the court handed down its decision concerning the interplay between the ADA and the Medicaid Act. The Arc argued that the ADA was violated by the state's limitation on the number of individuals who can receive waiver services. The court rejected this argument, deciding that the ADA does not override provisions in the Medicaid Act that permit a state to limit the number of HCBS waiver participants. The court based this decision on the principle that a specific statute (the Medicaid Act) is not controlled or nullified by a general statute (the ADA). As a result, the court dismissed the Arc's ADA claim.<sup>30</sup> However, the court remanded the case back to the district court to reconsider some aspects of its dismissal of the case. There has been no activity at the district court level since the Circuit Court ruling.

**Boyle v. Braddock.** This class action complaint (01cv5687) was filed by Columbia Legal Services in December 2001 in the U.S. District Court for Western Washington. The complaint alleges that Washington has failed to furnish or make available the full range of services offered through the Community Alternatives (HCBS waiver) Program (CAP) to program participants. The plaintiffs cited examples of individuals not receiving necessary services or not being informed of services offered in the program. This complaint somewhat paralleled the Arc of Washington State v. Quasim complaint but focused exclusively on the alleged problems that current waiver participants have in accessing the full range of CAP services. The proposed class is composed of all current or future CAP participants.

<sup>30</sup> The opinion is located at: [caselaw.lp.findlaw.com/data2/circs/9th/0335605p.pdf](http://caselaw.lp.findlaw.com/data2/circs/9th/0335605p.pdf).

Specifically, the complaint alleged that the state has: (a) violated §1902(a)(8) of the Act by not advising waiver participants of the availability of CAP services, failing to instruct them on how to request such services and not approving or providing needed services; (b) violated the requirement that the state put into place necessary safeguards to protect the health and welfare of participants; (c) failed to provide or arrange for appropriate assessments; (d) not furnished necessary services with reasonable promptness; (e) not permitted participants to exercise free choice of providers; (f) failed to provide participants with adequate written notice and an opportunity for a Fair Hearing when their service requests are denied, reduced or terminated; and, (g) deprived individuals of their property interest in Medicaid services without due process of law in violation of the 14<sup>th</sup> Amendment.

Proceedings in this case were stayed while the court weighed the settlement agreement in Arc of Washington State v. Quasim. When the court rejected that settlement, it lifted the stay on proceedings. State officials declared to the court that waiver policies had changed to make it clear that lack of funding "... is not a valid reason to deny a needed service to someone on the ... waiver." They also declared that they had made numerous other changes to waiver policies that addressed issues raised by the plaintiffs.

The state opposed class certification and raised other objections to the lawsuit. The state argued that changes already made in CAP in response to a CMS review had addressed the plaintiffs' issues. Also, the state asserted that it was converting CAP to four separate waiver programs and, hence, certifying the class with respect to the CAP program would be inappropriate.<sup>31</sup> The state also argued that there is no right of private action to enforce individual claims for Medicaid services in any event. Finally, because each person's situation should be addressed individually, the state contended that class certification would be inappropriate.

In April 2003, the court dismissed the case after denying class certification. The court concluded that the issues in question were the proper subject of state administrative procedures, which also provide for state judicial review in Washington. The plaintiffs countered that the issues in dispute were more properly addressed in a class action context and appealed the dismissal (03-35312) to the 9<sup>th</sup> Circuit Court.

This case was consolidated with *Arc of Washington State* for purposes of oral argument. Circuit proceedings in both *Arc of Washington State* and *Boyle*

had been suspended while the parties explored a mediated settlement. In mid-February, the parties notified the Court that they could not arrive at a settlement. In April 2005, the Circuit Court upheld the district court's decision in part and reversed the decision in part.

In September 2005, the plaintiffs filed an amended complaint, alleging that the state continues to fail in furnishing necessary waiver services with reasonable promptness. Plaintiffs also argue that how the state assigned waiver participants to the four waivers that replaced the CAP waiver deprived individuals of the opportunity to request a Medicaid Fair Hearing and exercise their due process rights under the U.S. Constitution. In particular, some individuals were assigned to a new waiver that provided less comprehensive services than the CAP waiver rather than to a waiver that covered the services that they require. Plaintiffs claim that these individuals should have had the right to appeal the assignment to a waiver that provides fewer benefits. Also in September, the state filed its answer to the amended complaint, arguing that the plaintiffs do not have standing to pursue relief in federal court and asserting 11<sup>th</sup> Amendment sovereign immunity. Trial is scheduled for September 2006.

## 25. West Virginia: Benjamin H. et al. v. Ohl

This class action complaint (99-0338) was filed in April 1999 in the U.S. District Court for the Southern District of West Virginia and alleged that West Virginia violated federal Medicaid law and the ADA by failing to provide Medicaid long-term services with reasonable promptness to eligible individuals. In July 1999, the court quickly granted the plaintiffs' motion for a preliminary injunction based on its finding that the plaintiffs were likely to prevail at trial based solely on the requirements of Medicaid law.<sup>32</sup> The state was ordered to develop a plan that would eliminate waiting lists; establish reasonable time frames for placing persons in the waiver; allow persons to exercise their freedom of choice in selecting institutional or home based care; and, develop written policies to inform persons of the eligibility process along with policies and forms to afford proper notice and an opportunity for a fair hearing when applications for ICF/MR level services are denied or not acted on with reasonable promptness.

In March 2000, the court approved agreements between the parties to address the topics spelled out in the preliminary injunction.<sup>33</sup> West Virginia agreed to increase the number of individuals with developmental

<sup>31</sup> CMS approved this change. The four waivers that replaced CAP provide for different services and levels of support.

<sup>32</sup> The decision is at: [healthlaw.org/pubs/199907benjamin.html](http://healthlaw.org/pubs/199907benjamin.html)

<sup>33</sup> The settlement order is at [healthlaw.org/docs/benh\\_order.pdf](http://healthlaw.org/docs/benh_order.pdf).

disabilities who receive HCB waiver services by 875 over a five-year period. The parties also agreed on revised procedures concerning service applications and giving individuals proper notice concerning the disposition of their applications. The state also submitted an application to HCFA to renew its HCBS waiver program, incorporating policy changes based required by the agreement and boosting the number of persons served. This request was approved in December 2000. The court dismissed this case in August 2002 but retained jurisdiction to enforce its orders.

#### **D. Lawsuits Involving Individuals with Other Disabilities**

There also have been several lawsuits filed on behalf of individuals with other disabilities who are seeking community services. In general, the legal issues raised in these lawsuits parallel those in lawsuits concerning persons with developmental disabilities. These lawsuits have been filed by nursing facility residents who want to be in the community as well as persons with disabilities who face institutionalization due to the lack of home and community services.

##### **1. Florida: *Dubois et al. v. Rhonda Medows et al.***

In April 2003, three individuals with traumatic brain or spinal cord injuries filed a class action complaint (03-CV-107) in the U.S. District Court for Northern Florida against the Florida Agency for Health Care Administration and Department of Health alleging that the state has violated Medicaid law and the ADA by failing to provide them Medicaid-funded long-term services in the community. These individuals had sought but not received community services through Florida's Brain or Spinal Cord Injury (BSCI) waiver program. The lawsuit alleges that there are 226 (and possibly more) individuals impermissibly wait-listed for services. One plaintiff resides in a nursing facility; the other two plaintiffs are in the community but at risk of institutionalization. The plaintiffs are represented by Southern Legal Counsel, a Gainesville non-profit public interest law firm and National Health Law Project attorneys.<sup>34</sup>

The plaintiffs argue that they all have sought but been denied BSCI services due to lack of funds even though it is alleged that only a little more than one-half of the program's approved slots are used. As a result, they have been unnecessarily segregated in nursing homes or are at imminent risk of segregation. The complaint charges that Florida has violated: (a) the ADA for failing to provide individuals with disabilities services

in the most integrated setting and not administering its waiting list so that it moves at a reasonable pace; (b) §504 of the Rehabilitation Act; (c) §1902(a)(8) of the Act for not making home and community services available with reasonable promptness; (d) §1915(c)(2)(C) for failing to give individuals the choice between institutional and HCB waiver services; and, (e) the U.S. Constitution and Medicaid law by not affording the plaintiffs the opportunity to apply for services. Class certification also was sought.

In May 2003, the state moved to dismiss the lawsuit, contending that, although its federally-approved HCBS waiver application had 300 "slots," the state had the latitude not to use all of them if appropriations were insufficient. In addition, the state argued on various grounds that, even if slots were available, it was not necessarily the case that the plaintiffs would be next in line to receive services. The state also objected to the plaintiffs' ADA and Rehabilitation Act claims.

In June 2003, the plaintiffs opposed the state's motion to dismiss. The plaintiffs argued that the state's motion was flawed in several respects, including raising issues that more properly should be addressed at trial. The plaintiffs pointed out that their claims might be remedied if the state had a comprehensive working plan for placing individuals in the community and a waiting list that moved at a reasonable pace, as provided in the *Olmstead* decision.

In March 2004, the court ruled on various motions. Specifically, the court denied the state's motion to dismiss, finding that the plaintiffs' claims had potential merit. The court also approved class certification, defining the class as: "All individuals with traumatic brain or spinal cord injuries who the state has already determined or will determine to be eligible to receive BSCI Waiver Program Services and have not received such services."

The lawsuit is being mediated. The parties are working toward finalizing a settlement agreement. Absent a settlement, trial is scheduled for July 2006.

##### **2. Georgia: *Birdsong et al. v. Perdue et al.***

In January 2003, private attorneys filed a class action complaint (03-CV-288) in the U.S. District Court for Northern Georgia on behalf of individuals with physical disabilities who reside in nursing homes and want community services or are at risk of nursing home placement if not furnished community services. The plaintiffs contend that Georgia's policies cause them to be unnecessarily segregated when they could be supported in the community. The complaint alleges that "[i]n the three and one-half years since the *Olmstead v. L.C.* decision, the State has made no

<sup>34</sup> Background information concerning the suit is at: [newswise.com/articles/2003/4/SLC.PIL.html](http://newswise.com/articles/2003/4/SLC.PIL.html)

significant effort to operate its long-term care services in an even-handed manner so that persons who need [home and community-based] services have this option.” The Olmstead decision concerned the unnecessary institutionalization of Georgians with disabilities.

The plaintiffs are persons who have severe physical disabilities and, except in one instance, reside in nursing facilities. They assert that, with appropriate supports, they could live in the community. Georgia operates two waiver programs – the Community Care Services Program and the Independent Care Waiver Program – for persons with disabilities. The plaintiffs are wait listed for these waivers; however, the waiting lists are quite lengthy. In their complaint, the plaintiffs contend that Georgia spends about five times as much on institutional as community services.

The plaintiffs allege that Georgia’s policies violate: (a) ADA and §504 of the Rehabilitation Act due to the state’s failure to furnish services in the most integrated settings and its utilization of discriminatory criteria and methods of administration in its programs; (b) §1915(c)(2)(C) of the Act for failing to provide timely and adequate notice to individuals who might benefit from waiver services and provide individuals freedom of choice between institutional and waiver services; and, (c) §1902(a)(8) of the Act for failing to promptly provide community services to individuals.

In April 2003, the state answered the complaint, denying that its policies violated the plaintiffs’ rights. The state also argued that the complaint did not state a claim for relief that the court could grant.

In August 2004, the plaintiffs filed a class certification motion. The proposed class would include all persons with physical disabilities who: “(1) are qualified to receive long-term health-care and supportive services under Medicaid and state-funded programs administered by the state, and, (2) would prefer, and are qualified (with or without reasonable accommodations) to receive such services in a more integrated setting than a nursing home ... but (3) are either unnecessarily confined and segregated in nursing homes, or on community-based services waiting lists that do not move at a reasonable pace.”

Also in August, the state moved to dismiss the plaintiffs’ Medicaid Act and Title II ADA claims. With respect to the Medicaid Act claims, the state argued that, based on the Supreme Court’s Gonzaga decision, the plaintiffs do not have standing because the Medicaid Act does not confer individually enforceable rights. With regard to the ADA, the state contended that Congress exceeded its authority when it enacted Title II and thus its provisions cannot be applied to the

administration of the state’s waivers. This challenge to Title II prompted the U.S. Department of Justice to intervene as an *amicus*.

In September 2004, the plaintiffs responded to the state’s motion to dismiss the Medicaid Act and ADA Title II claims. They argued that the Medicaid Act provisions at issue clearly include “rights creating” language and, therefore, satisfy the Supreme Court’s tests for bringing action under §1983. They also contended that Congress did not exceed its authority in enacting Title II and, thus, Title II is applicable to Medicaid services. In March 2005, the court disposed of various motions. The parties are in settlement discussions.

### 3. Indiana: *Inch et. al. v. Humphrey and Griffin*

In July 2000, the Indiana Civil Liberties Union filed this class action lawsuit in Marion County Superior Court on behalf of individuals with disabilities who reside in nursing homes or who are at risk of nursing home placement but want to live in integrated settings with services from Indiana’s HCB waiver for individuals who are elderly or disabled. The Indiana Family and Social Services Administration is the defendant. The lawsuit alleged that 2,000 individuals with disabilities are either on waiting lists for community services or suffering “unjustified institutional isolation” and, hence, experiencing discrimination prohibited by the ADA. The complaint pointed out that Indiana spent less than 9% of its elderly and disabled budget to support individuals in integrated home and community settings. It further alleged that new enrollments in the state’s community programs had been closed for two years and new applications were not being taken. The plaintiffs argued that people in nursing home facilities or at risk of nursing home placement must be given the choice of waiver services rather than *de facto* limited to institutional services. The plaintiffs sought preliminary and permanent injunctions to enjoin the state from continuing violations of the ADA and direct that Medicaid eligible individuals be offered community services.

In June 2003, the parties arrived at a settlement that applies to all nursing facility residents eligible for Indiana’s waiver program and individuals at imminent risk of nursing facility placement. The state has agreed to expand the waiver to serve an additional 3,000 individuals and provide more information about community services to nursing facility residents. This settlement reflects Indiana’s plan to reduce the use of nursing facilities in favor of expanding community services. In addition, the “settlement sets out specific criteria for assessing the community support needs of class members and requires the state to develop a

quality assurance plan for completing these assessments and discharges.” (Priaux 2003)

In December 2000, a second class action complaint was filed in St. Joseph County Superior Court (South Bend) on behalf of individuals with developmental disabilities placed in nursing facilities due to the lack of HCB waiver services. In September 2004, this lawsuit was settled. The state agreed to provide waiver services to 450 nursing facility residents with developmental disabilities over the next eight years. It is estimated that there are about 1,900 nursing facility residents with developmental disabilities statewide. In addition, the state agreed to meet face-to-face with the guardians of these residents to provide them with information about community alternatives.

**4. Kentucky: Kerr et al. v. Holsinger et al.  
Oregon: Watson et al. v. Weeks et al.**

These lawsuits are similar. Both were filed in response to state actions to narrow eligibility for Medicaid long-term services in order to reduce state spending to address budget deficits. In each instance, the state raised the threshold level of assessed functional impairment necessary to qualify for Medicaid long-term services. This caused individuals with disabilities and older persons to lose eligibility. Predominantly but not exclusively, the persons affected by these actions are supported in the community through the HCBS waiver program rather than nursing facilities. In both cases, the plaintiffs challenge whether the state’s modified standards for determining eligibility are reasonable under the provisions of §1902(a)(17) of the Act and whether the state properly terminated the services of these individuals. In both cases, federal courts are asked to rollback the new restrictions.

**Oregon.** Eligibility for long-term services is based on an assessment mechanism. There are 17 “levels” of assessed need. In February 2003, as part of its efforts to balance its budget, the state cut off services to individuals who qualified for long-term services at lower levels of assessed need. This action caused several thousand individuals to potentially lose their eligibility; most of whom were receiving waiver services. The state, however, provided that these individuals could ask for a reassessment. This resulted in services being restored for many but not all individuals. In the budget for the current biennium, the Legislature directed that services be resumed for all but six levels of need. However, the net effect of these changes still was to narrow eligibility and cause individuals to lose services. In implementing these cuts, the Oregon Department of Human Services amended its HCBS waiver to incorporate these changes.

In response to the eligibility restriction, the Oregon Advocacy Center filed suit in February 2003 in the U.S. District Court for Oregon (03-227) to enjoin the state from terminating benefits for affected persons. OAC argued that the state’s assessment process was flawed and, consequently, failed to constitute a reasonable standard for determining eligibility under federal law. OAC also argued that the state had not properly notified individuals that their eligibility would be terminated. In June 2003, the court turned down the request for a preliminary injunction. The court reasoned that Oregon was free to reduce its HCBS waiver because it is optional. In addition, relying on the *Gonzaga* decision, the court decided that affected individuals did not have an enforceable right to services. Immediately, OAC appealed the denial of the injunction to the 9<sup>th</sup> Circuit Court (03-35545).<sup>35</sup>

The magistrate judge assigned the case prepared “Findings and Recommendations,” recommending that the court dismiss all the plaintiff motions, based on the optional nature of waiver services and the interpretation that individuals do not have individually enforceable rights for Medicaid services. In June 2004, the district court accepted the magistrate judge’s findings and recommendations, dismissed the plaintiff motions and granted the state’s motion to dismiss. Meantime, because the state’s budget picture has brightened somewhat, in April 2004 the Oregon Legislature approved restoring additional two levels of assessed need, effective July 2004. In August 2004, the plaintiffs appealed the dismissal to the 9<sup>th</sup> Circuit (04-35704). Oral argument is set for November 2005.

**Kentucky.** In January 2003, Kentucky made \$250 million in Medicaid cuts in order to balance its budget. Among those cuts was an action to eliminate both nursing home and waiver services for individuals who had a “low intensity level of care.” This cut took effect in April 2003 and was expected to reduce Medicaid spending by \$41 million.

In October 2003, Kentucky Legal Services Programs filed a class action complaint (03-68) in the U.S. District Court for Eastern Kentucky seeking preliminary and permanent injunctions to rollback the eligibility change.<sup>36</sup> Attorneys with the National Senior Citizens Law Center assisted in this litigation. KLS alleges that the change in program eligibility criteria resulted in about 200 nursing facility residents and 1,200 HCBS waiver participants who are elderly and/or disabled losing eligibility. In addition, about 600 waiver

<sup>35</sup> Both the state and OAC briefs are located at: [nslc.org/news/03/07/appeal\\_watson.htm](http://nslc.org/news/03/07/appeal_watson.htm)

<sup>36</sup> Various materials, including the original complaint can be accessed at: [nslc.org/news/04/april/kentucky\\_preliminj.htm](http://nslc.org/news/04/april/kentucky_preliminj.htm).

applicants were denied services as a result of the change. As in the Oregon lawsuit, the plaintiffs challenge the state's method of assessing individuals and whether the state's procedures for terminating benefits met Medicaid and Constitutional requirements. The claims in this lawsuit roughly parallel those in the Oregon litigation.

In October 2003, the state moved to dismiss. In its motion, the state argued that the changes it made were well within the discretion afforded states in operating the Medicaid program. In addition, the state argued that the plaintiffs lack standing to bring suit in federal court because the Medicaid Act does not confer enforceable rights. The state also contended that, if it were required to roll back the changes, it might have no other choice but to eliminate its waiver program.

In November 2003, the plaintiffs moved for class certification and, in early December, responded to the state's motion to dismiss. The plaintiffs disputed the state's contention that the Medicaid Act does not confer enforceable rights, citing 6<sup>th</sup> Circuit rulings and other cases that ran counter to the state's arguments.

In early January 2004, newly elected Governor Ernie Fletcher signed an emergency order to reverse many of the changes that triggered the lawsuit. While encouraged by this step, the plaintiffs contended that the state had not gone far enough. As a consequence, they continued to press their case. In January 2004, the plaintiffs moved for a preliminary injunction, asking the court to require the state to roll its policies back to those in effect prior to the April 2003 change. In February 2004, the state filed a motion opposing the injunction and submitted a proposed order to dismiss the lawsuit.

In March 2004, the court ruled on the state's motion to dismiss and the plaintiffs' motion for a preliminary injunction. The court denied the state's motion, finding that federal Medicaid law provides the plaintiffs with individually enforceable rights. The court agreed with the plaintiffs' contention that Medicaid's comparability requirement (§1902(a)(10) (A) of the Act) and statutory provisions concerning the HCBS waiver program require that a state must make waiver services available to individuals who qualify for nursing facility services. The court also agreed with the plaintiffs that "there is no precedent that a state can alter eligibility for a mandatory Medicaid service simply because the state does not wish to pay the price required to provide the service to all eligible recipients." The court further observed that "reducing benefits to qualified recipients by manipulating eligibility standards in order to make up for budget deficits is unreasonable and inconsistent with

Medicaid objectives since it exposes recipients to 'whimsical and arbitrary' decisions ..." The court then granted the plaintiffs' motion for a preliminary injunction and ordered the immediate restoration of benefits to all persons who had lost them. In a separate order, the court also granted class certification.

In June 2004, the court gave its preliminary approval to a settlement agreement. Under the agreement, the State committed to adopt revised eligibility regulations for nursing facility and waiver services. The plaintiff attorney characterized these rules as more liberal than the rules in effect place prior to the April 2003 change that triggered the lawsuit. The settlement also provides for a re-evaluation of persons who were denied services under the previous rules. In August 2004, the Court gave final approval to the settlement agreement but decided to retain jurisdiction in the case for a period of two years.

##### **5. Louisiana: Barthelemy et al. v. Louisiana Department of Health and Hospitals**

In April 2000, five individuals (two with developmental disabilities and three with physical disabilities) along with Resources for Independent Living filed a complaint (00cv01083) in the U.S. District Court for Eastern Louisiana against the Louisiana Department of Health and Hospitals (DHH) alleging that the state was violating the ADA and §504 of the Rehabilitation Act by restricting the availability of services to "unnecessarily segregated settings" (i.e., nursing facilities). The plaintiffs with non-developmental disabilities sued for access to the state's elderly and disabled and/or personal care attendant waiver programs; the plaintiffs with cognitive disabilities wanted access to Louisiana's developmental disabilities and personal care attendant waiver programs. The plaintiffs charged that Louisiana spends "90% of its Medicaid funds on institutional services." They asked the Court to: 1) grant class action status to Louisianans with disabilities who are unnecessarily institutionalized and 2) find the state in violation of the ADA and §504 of the Rehabilitation Act.

In August 2001, DHH Secretary David Hood unveiled a settlement agreement that provided for boosting state spending by \$118 million over a four year period, provide community services to 1,700 more individuals and reduce waiting time for services to 90 days or less. The settlement plan submitted by DHH, agreed to by the plaintiffs and approved by the court addressed four broad areas: (a) reducing the waiting time for community-based services; (b) supporting people to make informed choices about service options; (c) adding a Medicaid state plan personal care services option; and, (d) instituting individualized long-term

care assessments through a new single point of entry system. The class certified for the agreement is composed of: "all persons with disabilities who are receiving Medicaid-funded services in nursing facilities, or who are at imminent risk of being admitted to a nursing facility to receive such services, who have applied for Medicaid-funded services in the community through one or more Medicaid-funded home and community-based waivers ... , who have not been determined ineligible for such community-based services, and who have not received such Medicaid-funded community-based services." In the agreement, the state committed to eliminate the waiting list for waiver services by 2005.

The agreement was later modified to delay the addition of entitled personal care services to the Medicaid state plan until July 2003; in exchange, the state agreed to add 500 more "slots" to its three waiver programs for adults with disabilities. The Louisiana Nursing Home Association objected to the personal care coverage but the court turned the objection aside. As a result of the expansion of waiver services, waiting lists have been reduced substantially.

In 2003, DHH submitted a \$38 million request to the Louisiana legislature to fund the addition of personal care to the Medicaid state plan. But, the legislature balked at this request. Instead, it appropriated \$28 million, instructed DHH to delay adding personal care to the Medicaid state plan, and directed state officials to return to court to seek a modification of the settlement agreement to expand waiver programs in lieu of adding personal care to the state plan. The Legislature expressed concern about the long-range costs of adding a new entitlement to the state's Medicaid program. The plaintiffs warned that they would regard failure to implement this part of the settlement as a material breach.

In July 2003, as directed by the legislature, the state filed a motion to amend the settlement agreement. The state proposed to expand waiver programs to serve an additional 2,000 individuals instead of adding personal care coverage. In support, the state pointed out that more class members would qualify for waiver services than the state plan service because the waiver program has higher income eligibility thresholds. Also, the state argued that class members could access a wider range of services through the waiver. The state argued that the proposed expansion was sufficient to serve all remaining individuals waiting for services and individuals who would be likely to seek services in the near to mid-term. Lastly, the state argued that the legislature has shown a willingness to underwrite the costs of expanded waiver services and thereby using

the waiver program to meet the needs of class members would provide stable funding.

The Louisiana Advocacy Center (LAC), which represents the plaintiffs, opposed changing the agreement. The plaintiffs argued that – absent an entitled personal care benefit – there was a danger that waiting lists would reemerge in Louisiana. In August 2003, LAC moved that the court enforce the settlement agreement. In its motion, LAC argued that was no material change to justify a change in the agreement. LAC pointed out that the coverage of personal care services had been expressly included in the settlement agreement to ensure that individuals have immediate access to services whether or not waiver slots were available. LAC also pointed out that the personal care benefit would provide more hours per week of services than were available through the waiver program and, furthermore, individuals served in the waiver program could also access state plan personal care benefits. LAC urged the court to order the state to implement state plan personal care services as rapidly as possible.

National AARP filed an *amicus* brief in support of the LAC motion. In the meantime, nursing home interests moved to intervene in support of the state's proposed modification, expressing concern that the activating the personal care option might put their businesses at risk. In August 2003, the state replied to the plaintiff motion in opposition. The state reiterated that it was not seeking to escape its obligations but only to alter how services are provided.

In September 2003, the court denied the state's motion to modify the settlement, directed it to comply with the settlement order and rejected the nursing home request to intervene. However, the court turned down the plaintiffs' request that the court enforce the settlement agreement. DHH affirmed it would comply with the court order. The Legislature then gave DHH officials the go ahead to submit a Medicaid plan amendment to add personal care but directed that DHH return to the Legislature for approval in the event that CMS required modifications in the plan amendment.

After encountering some initial difficulties securing CMS approval of the plan amendment, the state got the go ahead to offer personal care in January 2004.<sup>37</sup> State officials expected that 2,300 individuals would receive personal care by June 2004. Reportedly, within three weeks of the program's launch, the state had received 1,000 applications.<sup>38</sup> However, due to delays in

<sup>37</sup> A press release announcing the initiation of the program is at: [dhh.state.la.us/news.asp?Detail=216](http://dhh.state.la.us/news.asp?Detail=216)

<sup>38</sup> For more information concerning the "successes and challenges" stemming from this lawsuit, please go to [advocacyla.org/whatsnew.html](http://advocacyla.org/whatsnew.html).

processing applications, LAC returned to court in July 2004 to demand that the state establish timelines for prompt action on requests for personal care services. In August 2004, the state opposed the plaintiff motion that the court intervene to enforce the agreement. The state argued that it had done all that was possible to expand services and court intervention was not appropriate. Later that month, the court refused to intervene.

#### **6. Michigan: Eager et al. v. Granholm et al.**

In March, 2002, six individuals and five advocacy organizations filed a lawsuit (5-02-00044-DWM) in the U.S. District Court for Western Michigan to overturn the state's freeze on enrollments to the MIChoice Program, a Medicaid waiver program for persons with disabilities and seniors otherwise eligible for nursing facility services. The approved capacity of the MIChoice program was 15,000 individuals. As a result of an October 2001 freeze on enrollments, the plaintiffs contended that fewer than 11,000 individuals were participating in the program even though service demand remained high. The lawsuit was filed by Michigan Protection and Advocacy Services and the Michigan Poverty Law Program with support by a coalition of disability advocacy organizations.

The plaintiffs advanced two major legal claims. The first is that the freeze on enrollments violates the ADA by forcing individuals to seek nursing facility care rather than receive services in the most integrated setting. The second claim was that Michigan – under the terms of the waiver as approved – cannot close enrollments so long as fewer than 15,000 individuals participate. The plaintiffs also claim that Michigan did not provide individuals a choice between institutional and waiver services, maintain a proper waiting list for the MIChoice program, and violated the reasonable promptness requirement. The proceedings were put on hold to give newly-elected Governor Granholm's administration time to formulate its position concerning the litigation. The Governor subsequently announced that she was reopening program enrollments to a limited extent.

In December 2003, the parties submitted a proposed settlement agreement to the court. In part, the agreement provides that the state will: (a) provide for no less than \$100 million in funding for MIChoice in the current fiscal year, ask the legislature to approve a change in Medicaid policy that would permit an additional \$25 million to be allocated to MI Choice, and pursue additional changes that might result in yet another \$25 million to be allocated to the program; (b) distribute informational materials concerning MI Choice services to individuals receiving Medicaid long-term care services and make them available to

future applicants; (c) ensure that individuals choosing between waiver and institutional services are provided information about the full-range of available long-term services, including MI Choice; (d) adopt uniform medical/functional eligibility criteria that apply equally to waiver and nursing facility services; (e) develop procedures regarding the maintenance of waiting lists and obtain CMS approval for these procedures; (f) seek more funding for transitional services to individuals moving from nursing facilities to the community; and, (g) establish a Medicaid Long Term Care Task Force to develop options to expand the availability of home and community services and improve long-term services. In February 2004, the Court approved the settlement agreement.

#### **7. Mississippi: Billy A. and Mississippi Coalition for Citizens with Disabilities v. Jones et al.**

In May 2002, the Coalition for Citizens with Disabilities filed a class action complaint (02cv00475) on behalf of the five nursing facility residents in the U.S. District Court for Southern Mississippi alleging that Mississippi's policies lead to the unnecessary segregation of individuals with disabilities in nursing homes by not making home and community services available to them. The named defendants are the state's Division of Medicaid and the Departments of Human Services and Rehabilitation Services. Plaintiffs allege that the state is violating: (a) the ADA and §504 of the Rehabilitation Act by failing to provide Medicaid services in the most integrated setting; (b) the Medicaid Act by not informing individuals who qualify for nursing facility services of feasible alternatives to institutionalization and thereby denying them the freedom to choose home and community services as an alternative; (c) §1902(a)(8) of the Act by not providing services with reasonable promptness; and, (d) §1902(a)(30)(A) by not making payments for Medicaid services that are "consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers." (Priault, 2004). The court granted class certification in September 2003.

In March 2005, the parties submitted a settlement agreement to the court. The court approved the agreement and dismissed the lawsuit. The agreement provides that: (a) the state will implement a screening process to determine whether nursing facility residents can be supported in the community; (b) put nursing facility residents who want to return to the community on the referral list for waiver services; (c) provide up to \$800 for housing and utility deposits and moving expenses to assist nursing facility residents to return to the community; (d) increase payments to personal care

attendants by \$0.50 per hour; and, (e) make additional changes to improve access to community services.<sup>39</sup>

### 8. New Hampshire: Bryson et al. v. Shumway and Fox

In December 1999, two persons with neurological disabilities who reside in nursing facilities but are wait listed for the New Hampshire's Acquired Brain Disorder (ABD) "model" HCBS waiver program filed a class action complaint (99-cv-558) in the U.S. District Court for New Hampshire to gain access to community services. The plaintiffs alleged that the program is operated with "inadequate, capped funding through the HCB/ABI program, arbitrary limits [on] home health and other HCB services, and lack of coordination between the various public and private agencies which administer the Medicaid program."

The plaintiffs argued that "states must ensure that services will be provided in a manner consistent with the best interests of the recipients" and that a state's Medicaid program must be "sufficient in amount duration, and scope to reasonably achieve its purpose." Moreover, they argued that the state's "administration of the HCB/ABI program, which results in a failure to provide [HCB] services to eligible Medicaid recipients in a timely manner, defeats the purpose of the program and is insufficient in the amount, duration, and scope to reasonably achieve its purpose." The plaintiffs made additional claims, including: 1) failure to provide Medicaid services in a "reasonably prompt manner;" 2) violation of the ADA by making mainly facility-based services available to eligible persons; and, 3) the due process clause of the 14<sup>th</sup> Amendment as well as other provisions of Medicaid law.

In October 2001, the court handed ruled on both parties' motions for summary judgment.<sup>40</sup> It dismissed two of the seven counts in the complaint, ruled in the plaintiffs' favor on a third and decided a fourth was moot. However, the court deferred judgment on three central issues: (a) whether wait listing individuals violates Medicaid law concerning reasonable promptness; (b) whether New Hampshire's policies are at odds with the ADA; and, (c) whether the state's policies violate §504 of the Rehabilitation Act. The court rejected the state's motion to dismiss on 11<sup>th</sup> Amendment grounds.

In December 2001, the court entered a final order. It found that HCBS waiver services must be furnished with reasonable promptness and that individuals are entitled to model waiver services until 200 persons are

served. Federal law provides that the Secretary of Health and Human Services may not limit model waiver programs to fewer than 200 individuals. The order incorporated a stipulated agreement between the parties that eligible individuals be enrolled in the program within twelve months of their date of eligibility.

The state appealed the district court ruling to the 1<sup>st</sup> Circuit Court of Appeals. In October 2002, the Circuit ruled that the district court erred in its interpretation of §1915(c)(10) of the Social Security Act.<sup>41</sup> The district court interpreted the statute to require that a model waiver program must serve no fewer than 200 individuals. The Circuit found that this provision instead barred the Secretary of HHS from denying a state's request to serve up to 200 individuals but that a state could limit the number of individuals in a model waiver to fewer persons. The Circuit vacated the district court order that the state expand its waiver to serve at least 200 individuals in its program. But, the Circuit also made it clear that the state was obligated to furnish waiver services to individuals with reasonable promptness up to the limit it had established, characterizing the waiver participant cap as a limitation on eligibility. The Court also affirmed that the plaintiffs had standing to pursue their claims in federal court under §1983. The Circuit remanded the case to the district court to determine whether changes that New Hampshire had made in its notice provisions complied with federal requirements and whether the state operated the waiver in accordance with the reasonable promptness requirement up to the participant cap.

Upon remand, the parties renewed their motions for summary judgment. In March 2004, the court denied both motions. In its order, the court pointed out that the 1<sup>st</sup> Circuit's decision had effectively reduced the legal issues to those that revolve around the ADA and the principles laid down in the *Olmstead* decision. The court noted that its task was now to sort out New Hampshire's policies in light of the *Olmstead* decision, a task that would require it to grapple with several complex questions, including whether New Hampshire's waiting list is moving at a reasonable pace and the dividing line between "reasonable modifications" and "fundamental alteration." The court indicated that it would not necessarily confine its consideration of these issues to the ABI waiver but might take into account the overall resources that might be available to meet the plaintiffs' needs. In denying the motions for summary judgment, the court noted that neither party had presented sufficient

<sup>39</sup> A notice of this agreement is at: [mscoalition.com/page6.html](http://mscoalition.com/page6.html)

<sup>40</sup> This decision is found at: [nhd.uscourts.gov/](http://nhd.uscourts.gov/) (by searching "opinions" for keyword "Bryson").

<sup>41</sup> The Circuit Court decision is at [ca1.uscourts.gov/cgi-bin/getopn.pl?OPINION=02-1059.01A](http://ca1.uscourts.gov/cgi-bin/getopn.pl?OPINION=02-1059.01A).

evidence to permit it to rule on the ADA/Olmstead claims. Trial is scheduled for October 2005.

### 9. Washington: Townsend v. Quasim

Filed in the U.S. District Court for the Western District of Washington in 2000 (00-cv-00944), this lawsuit challenged Washington State's policy of not extending eligibility for its Medicaid Community Options Program Entry Services (COPEs) HCBS waiver program to "medically needy" individuals. Washington State limited eligibility for this program to individuals who are "categorically needy," including persons whose income is less than 300% of the federal SSI benefit. Medically needy individuals (e.g., persons whose income exceeds categorically needy levels but who may spend down their income to qualify for Medicaid) may not participate in this program but they are eligible for nursing facility services. In this instance, the plaintiff had been participating in the COPEs program but a slight increase in his income caused his status to change to medically needy. The state initiated action to terminate him from the COPEs program and suggested that the plaintiff seek care in a nursing facility. The plaintiff filed suit, arguing that the state's policy violated the ADA because he could not continue to receive services in his own home. The complaint was certified as a class action.<sup>42</sup>

In 2001, the district court ruled in the state's favor. The Court found that the state was exercising its prerogative under the Medicaid Act to limit the services it provides to medically needy individuals. Under Medicaid law, coverage of medically needy individuals is optional for the states. In addition, a state is not required to offer the same services to medically needy persons that it offers to categorically needy beneficiaries. In light of this latitude, the district court decided that the state's policy did not violate the ADA.

<sup>42</sup> Another lawsuit challenging a state's Medicaid financial eligibility policies for home and community-based services is Hermanson et al. v. Commonwealth of Massachusetts et al (00-cv-30156). This class action complaint challenged the state's policy of applying more restrictive financial eligibility criteria to seniors than working age adults with disabilities. In essence, Massachusetts permitted younger persons with disabilities to qualify for Medicaid without spend down if their income did not exceed 133% of poverty but older persons faced spend down requirements when their income exceeded 100% of poverty. As a consequence, older persons could less readily access Medicaid personal assistance services than younger persons and, thus, the plaintiffs argued, were placed at greater risk of institutionalization. The plaintiffs claimed this policy violated the ADA's integration mandate and its non-discrimination provisions. This lawsuit was settled in February 2003 when the state agreed to adopt more liberal financial eligibility criteria for older persons who need personal assistance. (Priaux, 2003)

In 2001, the plaintiffs appealed this decision to the 9<sup>th</sup> Circuit (01-35689). In May 2003, a three-judge Circuit Court panel reversed the decision by a 2-1 margin and remanded the lawsuit back to the district court for reconsideration.<sup>43</sup> The majority based its reversal on the ADA "integration mandate," deciding that Washington's policy of offering only nursing facility services to medically needy individuals would result in their needless segregation in institutional settings. However, a strong dissent was filed.<sup>44</sup> The dissenting judge took the majority to task for failing to reconcile the ADA integration mandate with the latitude afforded states under the Medicaid Act and, implicitly, requiring Washington State to expand services by requiring the state to make what amounted to a fundamental alternation in its programs. Immediately, the state petitioned the Circuit for a rehearing *en banc*. This petition was rejected in June 2003.

In January 2004, the parties entered into a stipulated settlement agreement. Under the terms of the agreement, court proceedings were stayed, contingent on the state's securing federal approval of a new HCBS waiver program for persons who are medically needy. The state then secured funding for this program from the legislature and CMS approved the state's waiver request. The new program was implemented in June 2004 and limits services to no more than 200 individuals. The plaintiffs reserved the right to reinstate the lawsuit if a waiting list for enrollment into the new waiver program emerges.

<sup>43</sup> Decision is at: [caselaw.findlaw.com/data2/circs/9th/0135689P.pdf](http://caselaw.findlaw.com/data2/circs/9th/0135689P.pdf)

<sup>44</sup> The dissent is included in the file containing the majority opinion at the foregoing URL.

### III. Community Placement of Institutionalized Persons

#### A. Overview

There is a long history of litigation concerning institutionalized persons with disabilities, dating back to the landmark Alabama Wyatt v. Stickney lawsuit in 1970.<sup>45</sup> In developmental disabilities services, this litigation revolved mainly around the conditions of public institutions and their lack of adequate and appropriate services. Over time, this litigation increasingly came to focus on the question of the necessity of institutional placement and led to court directives to place institutional residents in the community. There has been similar litigation concerning individuals confined to state mental health facilities.

The U.S. Supreme Court's historic 1999 Olmstead decision ruled that the unnecessary segregation of individuals with disabilities in institutions constitutes prohibited discrimination under the ADA. In its majority opinion, the Court concluded that Title II of the ADA requires a state to place institutionalized persons with disabilities in community settings when: (a) the state's treating professionals have determined that a community placement is appropriate; (b) the transfer from an institution to a more integrated setting is not opposed by the affected individual; and (c) the placement can be reasonably accommodated, taking into account the resources available to the state along with meeting the needs of other persons. In the wake of the Olmstead decision, there have been several lawsuits concerning persons served in public institutions.

This part of the report tracks some of the lawsuits where the issue of the community placement of institutionalized persons has been engaged and where the principles set down by the Supreme Court are being adjudicated. In these lawsuits, Medicaid policy is typically not the main focus of litigation, although the Medicaid program might help underwrite the costs of community placement. Also included are lawsuits concerning individuals with mental disabilities who reside in nursing facilities where issues concerning community placement have arisen.

We also acknowledge that there have been several lawsuits filed to oppose the community placement of institutionalized persons with developmental disabilities. Many of these lawsuits have been filed in state court by institutional parent groups who are sometimes

<sup>45</sup> It is worth noting that, in December 2003, the Wyatt case was dismissed 33-years after the complaint was originally filed. The court found that Alabama had satisfactorily implemented a settlement agreement that was entered into in 2000. For more information: [bazelon.org/newsroom/12-15-03wyatt.htm](http://bazelon.org/newsroom/12-15-03wyatt.htm).

aligned with public employee associations. Often, these lawsuits revolve around the question of the standing of guardian parents to refuse consent for community placement. The outcome of some of these lawsuits has been to slow but not halt the closure of state facilities.

#### B. Description of Lawsuits

##### 1. Arkansas: Porter and Norman v. Knickreim et al.

In October 2003, two residents of the Southeast Arkansas Human Development Center filed suit (03-CV-812) in the U.S. District Court for Eastern Arkansas against state officials to challenge the constitutionality of the admission and discharge procedures at Arkansas' six large institutions for persons with developmental disabilities. The plaintiffs claim that the state's not providing for judicial hearings to determine whether they must continue to be confined at a Human Development Center violates the Due Process and Equal Protection clauses of the 14<sup>th</sup> Amendment. Under Arkansas state law, the parents of an individual with mental retardation may petition for their voluntary admission to a state facility and persons so admitted may be discharged at the request of parents. However, there is no provision for judicial review of the continued placement of an individual at a facility. The plaintiffs are asking the court to declare Arkansas' policies unconstitutional and to direct the state to institute appropriate judicial review procedures. This complaint was filed on behalf of the plaintiffs by the Arkansas Disability Rights Center, the state's P&A.<sup>46</sup> In February, 2004, the court turned aside the state's motion to dismiss the lawsuit. While dismissing the plaintiffs' Equal Protection claims, the court decided that there was a potential basis for their Due Process claims. In addition, the court permitted an association of Human Development Center families to intervene. In March 2004, the plaintiffs filed a second amended complaint. In July and August 2004, the plaintiffs and the state moved for summary judgment.

In November 2004, the court ruled on summary judgment motions. It decided that Arkansas admission policies met due process tests but ordered the state to develop post-admission review procedures to ensure that individuals admitted as a result of a parent/guardian petition would not be unnecessarily confined in an HDC when they have been determined to benefit from community placement.

<sup>46</sup> There is additional information at: [arkdisabilityrights.org/law/alerts.html](http://arkdisabilityrights.org/law/alerts.html)

## 2. California: Davis et al. v. California Health and Human Services Agency et al.

In 2000, a class action complaint<sup>47</sup> was filed in the U.S. District Court for the Northern District of California on behalf of present and potential residents of Laguna Honda Hospital (a 1,200-bed nursing facility in San Francisco). This lawsuit was triggered when plans were announced for a \$400 million renovation of the facility. The complaint argued that the City and County of San Francisco (which operates the facility) along with several state agencies were violating federal Medicaid law and the ADA by denying individuals with disabilities access to community services and thereby forcing them to remain or become institutionalized. Plaintiffs are represented by a coalition of disability and advocacy organizations. The US Department of Justice also filed a friend of the court brief in support of the plaintiffs. In August 2001, the Court rejected San Francisco's motion to dismiss the lawsuit. The facility has been the subject of an ongoing investigation by USDOJ under the provisions of the Civil Rights for Institutionalized Persons Act (CRIPA). In April 2003, USDOJ wrote the City of San Francisco that it had found the operation of the facility did not comport with the principles enunciated by the Supreme Court in *Olmstead* decision. USDOJ faulted discharge planning at the facility and noted that many residents had been identified who could be served in a more integrated setting. It urged the City to increase the availability of home and community services and make other changes. Absent resolution of these issues, USDOJ warned that the Attorney General might institute a lawsuit to correct the deficiencies.

In December 2003, the court gave preliminary approval to settlement agreements between the plaintiffs, the city and the state.<sup>48</sup> Under the agreement, the city will launch a targeted case management program to assess current residents and potential admissions to the facility to determine whether other community alternatives could be furnished to them instead. Also, the city agreed to furnish information about community services to current residents and take additional steps to encourage the use of community alternatives. In addition, California will revamp its pre-admission screening program for individuals with psychiatric disabilities to place greater emphasis on community alternatives to nursing home placement. The settlement, however, does not stop the renovation of

the facility, which began in November and is expected to be completed in 2007. The plaintiffs have reserved the option to refile elements of the lawsuit that involve the community placement of facility residents. This option might be invoked if sufficient community alternatives are not provided.

## 3. California: Capitol People First et al. v. California Department of Developmental Services et al.

This class action complaint was filed in January 2002 in Alameda County Superior Court by California Protection and Advocacy, Inc. on behalf of 12 individuals with developmental disabilities served in state Developmental Centers or other large congregate facilities (including nursing facilities), three community organizations and two taxpayers. The lawsuit was filed against the Departments of Developmental Services, Health Services and Finance along with California's Health and Human Services Agency and the 21 non-profit Regional Centers that manage community services for people with developmental disabilities.

The lawsuit charges that California has caused thousands of individuals to be "needlessly isolated and segregated" in large congregate public and private facilities and further contends that the lack of appropriate community services causes persons with disabilities to be put at risk of institutionalization. The plaintiffs argue that California's policies violate the state's Lanterman Act (especially its "integration mandate") and Constitution along with the ADA, federal Medicaid law, §504 of the Rehabilitation Act and the federal Constitution. The Lanterman Act governs the delivery of services for persons with developmental disabilities and requires that all eligible persons be provided services. The plaintiffs have asked the court to certify a class of "all Californians with developmental disabilities who are or will be institutionalized, and those who are or will be at risk of institutionalization in either public or private facilities, including but not limited to, the Developmental Centers, skilled nursing facilities, intermediate care facilities (ICF/DDs), large congregate care facilities, psychiatric hospitals or children's shelters." If the class is certified as proposed, it would include roughly 6,000 persons residing in large congregate facilities and an estimated 400 individuals who are at risk of institutionalization each year. According to the plaintiffs, some 1,000 of the 3,700 persons served at the state's Developmental Centers have been recommended for discharge to the community but continue to be inappropriately institutionalized.

The lawsuit asks the Court to order sweeping changes in California's services for people with developmental

<sup>47</sup> The complaint is located at [dredf.org/final.html](http://dredf.org/final.html).

<sup>48</sup> A description of the settlement agreement along with the agreements are located on the Bazelon Center website at: [bazelon.org/newsroom/1-5-04davis\\_settlement.htm](http://bazelon.org/newsroom/1-5-04davis_settlement.htm). More information also is available at: [pai-ca.org/BulletinBoard/DavisvsLHHSettlement.htm](http://pai-ca.org/BulletinBoard/DavisvsLHHSettlement.htm).

disabilities, including requiring the state to offer the full range of Medicaid home and community-based services to individuals and strengthening other dimensions of community services.<sup>49</sup> In March 2002, the court decided to treat the lawsuit as “complex litigation” (2002038715) and assigned it a division expressly charged with handling such cases. In November 2002, the California Association of State Hospital Parent Councils for the Retarded (CASH/PCR) and the California Association for the Retarded (CAR) petitioned to intervene in the litigation. These associations are composed of parents of individuals served in state-operated facilities. They sought intervenor status because they do not believe that the defendants will adequately represent the interests of institutionalized persons who might be endangered by community placement. This petition was opposed by the plaintiffs along with some Regional Center defendants. In January, 2003, the Court gave the parents leave to intervene but confined the scope of their intervention to the “parameters of the complaint.” The court admonished the intervenors not to attempt to enlarge the issues in the litigation and confine themselves to two issues: “ensuring that the legal rights of parents to participate in the planning process and the ability of professionals to recommend placement in developmental centers are not adversely affected by any judgment in this action.”

In August 2003, the state defendants (as distinct from the Regional Center defendants) filed a motion for summary adjudication concerning the plaintiffs’ Lanterman Act claim to enforce the Act through court-issued “writs of mandate.” The state argued that the Lanterman Act creates only discretionary duties upon the state defendants and thereby the court cannot compel action because the Act does not create a “mandatable duty” with respect to alleged violations. In addition, the state filed a motion to throw out the plaintiffs’ claim that the state’s policies violate the federal Medicaid Act.

In November 2003, the court handed down tentative rulings on the state’s motions. With respect to whether the Lanterman Act creates a mandatable duty that courts can enforce through writ proceedings, the court decided in the state’s favor and dismissed this cause of action. However, the Court noted that its dismissal did not address “whether Defendants are in compliance with the Lanterman Act or whether it can be enforced through other means.” The Court also dismissed plaintiff claims alleging violations of the federal Medicaid Act. The Court was persuaded by the state’s argument

that the Medicaid Act does not create a right of private action for individual beneficiaries, concluding that the Act “merely describes what states must do to ensure continued [federal] funding and authorizes the Secretary to withhold or limit Medicaid payments to a state in violation of [its] provisions.” In reaching this conclusion, the Court was persuaded by the federal district court decision in the Utah DC v. Williams litigation (see above) where the Court decided that the application of the U.S. Supreme Court’s Gonzaga decision led to the conclusion that the Medicaid Act does not confer individually enforceable rights. Still to be decided are the plaintiffs’ other claims, including their claims under the ADA and Rehabilitation Act as well as federal and state constitutional claims.

In December 2003, the Court clarified its November decision. The Court decided that, while it could not use a writ of mandate to remedy any wrong under the Lanterman Act, there was the potential that it could use injunctive relief to remedy violations of the Act. In addition, the Court gave the plaintiffs more time to fashion their petition for class certification. January 2004, the state filed a motion arguing that injunctive relief also could not be used to remedy violations of the Lanterman Act and asked the court to dismiss claims based on the Act. In February 2004, the court denied the state’s motion. Also, in February 2004, the plaintiffs filed their motion for class certification and a hearing on the motion was scheduled for April 2004.

In April 2004, the state petitioned the California Court of Appeal in San Francisco to stay proceedings in the lawsuit until the court could review the lower court’s Lanterman Act rulings. The Court of Appeal granted the stay. In its petition, the state once again argued that the Lanterman Act does not create a judicially enforceable “mandate” that requires people with disabilities to be served in the least restrictive setting. Instead, the statute should be regarded as merely intent language with implementation of the Act left to state and regional center discretion. The Court of Appeal issued a writ vacating the lower court’s Lanterman Act rulings. However, the Court gave the plaintiffs the leeway to amend their complaint to reinstate a violation of the Lanterman Act as a cause of action.

In July 2004, the plaintiffs filed an amended complaint. They also petitioned the court to reinstate their claims of violations of the Medicaid Act, citing rulings in other cases that ran contrary to the court’s view that Medicaid beneficiaries do not have individually enforceable rights, based on the Gonzaga decision. The State objected to the reassertion in of Lanterman Act claims in the amended complaint. A hearing was held in late September concerning the reinstatement of the

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<sup>49</sup>.More information is at [pai-ca.org/BulletinBoard/Index.htm#CPF](http://pai-ca.org/BulletinBoard/Index.htm#CPF)

Medicaid Act claims and the state's objections to the renewed Lanterman Act claims.

In January 2005, the court ruled that the plaintiffs' could go forward to trial on their claim that the State has failed to exercise its discretion consistent with the statutory principles of the Lanterman Act and Medicaid laws. The state had again challenged the sufficiency of the complaint, arguing, in essence, that it has unbridled discretion, and thus cannot be sued for how it implements the Lanterman Act or Medicaid laws.

The state appealed this decision. In March 2005, the Court of Appeal denied the state's petition stating. According to Protection & Advocacy attorneys, the "ruling means that plaintiffs in this case, and regional center consumers, generally, can enforce the requirements of the Lanterman Act and the Medicaid Act including the least restrictive environment, or integration, requirements if the state is not exercising its discretion within the proper limits or under a correct interpretation of the law."

#### 4. Florida: Brown et al. v. Bush et al.

This 1998 class action complaint (98cv673) was filed in the U.S. District Court for Southern Florida and sought a declaratory judgment and permanent injunction to prevent the state from unnecessarily institutionalizing individuals with developmental disabilities in violation of the ADA integration mandate, §504 of the Rehabilitation Services Act, Medicaid law, and the U.S. Constitution. In March 1999, the U.S. District Court for the Southern District of Florida certified the Plaintiffs' proposed class of: "all persons who on or after January 1, 1998, have resided, are residing, or will reside in DSIs [Developmental Services Institutions] including all persons who have been transferred from [institutions] to other settings, such as ICF, group homes, or SNFs but remain defendant's responsibility; and all persons at risk of being sent to DSIs."

Florida appealed the class certification to the 11<sup>th</sup> Circuit. In 2000, The 11<sup>th</sup> Circuit agreed that the proposed class was overly broad and remanded the case to the district court with instructions to certify the class as composed of "all individuals with developmental disabilities who were residing in a Florida DSI as of March 25, 1998, and/or are currently residing in a Florida DSI who are Medicaid eligible and presently receiving Medicaid benefits, who have properly and formally requested a community-based placement, and who have been recommended by a State-qualified treatment professional or habilitation team for a less restrictive placement that would be medically and otherwise appropriate, given each individual's particular needs and circumstances."

After extended negotiations and with the assistance of a mediator, the parties arrived at a settlement agreement. In July 2004, a final proposed agreement was presented to the court for review. The agreement provides that, by June 2005, the state will prepare a plan to close Gulf Coast Center and close the facility by 2010. Coupled with the closure of Community of Landmark (another DSI located in Opa Locka) that is slated for June 2005, the agreement will reduce from four to two the number of facilities that Florida operates. The agreement also provides for earmarking HCBS waiver "slots" to accommodate the transition of individuals from DSIs to the community, beginning in FY 2005.

The September 2004 notice of the proposed settlement agreement triggered numerous objections from groups and individuals interested in preserving institutional services. In December 2004, court held a fairness hearing concerning the proposed settlement. Following the fairness hearing, a group of objectors filed an appeal at the 11<sup>th</sup> Circuit Court of Appeals. The Circuit denied objectors' petition. The district court then approved the settlement order in August 2005. The objectors then filed a new appeal with the 11<sup>th</sup> Circuit in September 2005.

#### 5. Illinois: Ligas et al v. Maram et al.

This class action complaint was filed in July 2005 in U.S. District Court for the Northern District of Illinois. The complaint alleges that Illinois' policies result in the unnecessary institutionalization of individuals with developmental disabilities in large, congregate privately-operated ICF/DD facilities when such individuals could be supported in more integrated settings in the community. The plaintiffs are represented by Equip for Equality (the Illinois Protection and Advocacy agency), Access Living, the American Civil Liberties Union of Illinois, the Public Interest Law Center of Philadelphia, and a private law firm serving as trial counsel on a *pro bono* basis.<sup>50</sup>

In Illinois, there are 250 large ICF/DD facilities that serve approximately 6,000 individuals. The complaint contends that Illinois prevents residents who reside in these facilities from accessing more integrated home and community waiver services and forces other individuals to accept ICF/DD services when community services would meet their needs. This is the first lawsuit of this type that focuses exclusively on potential violations of the Olmstead decision in privately-operated ICF/MR facilities.

<sup>50</sup> A press release concerning this lawsuit is located at: [equipforequality.org/news/pressreleases/july\\_28\\_2005illinois\\_residents.php](http://equipforequality.org/news/pressreleases/july_28_2005illinois_residents.php)

In particular, lawsuit alleges that Illinois is violating: (a) Title II of ADA; (b) §504 of the Rehabilitation Act; (c) several provisions of Medicaid law, including §1902(a)(8) (reasonable promptness), §1915(c)(2)(C) (choice between waiver and institutional services), and §1902(a)(30)(B) (by fostering unnecessary utilization of ICF/MR services) and §1983.<sup>51</sup>

In September 2005, the state answered the complaint. In essence, the state contends that how it administers Medicaid services complies with federal law and further challenged whether the plaintiffs have standing to bring suit.

#### 6. Maryland: Williams et al. v. Wasserman et al.

This 1994 lawsuit (CCB-94-880) was filed in the U.S. District Court for Maryland against Maryland Department of Mental Health and Hygiene by institutionalized persons who had a traumatic brain injury or another developmental disability and were demanding that the state provide community services to them. The plaintiffs' alleged that Maryland violated (a) the U.S. Constitution by unnecessarily confining them to institutions and (b) the ADA by not furnishing them services in the most integrated setting. In 1996, the Court denied both parties' motions for summary judgment. Finally, in September 2001, the court dismissed the lawsuit,<sup>52</sup> finding that Maryland had made a good faith effort to (a) meet the needs of the plaintiffs and (b) accommodate individuals in the community.

This lawsuit was filed prior to the Olmstead decision. The district court's final decision came after the Olmstead decision and hinged in part on the court's view that ordering Maryland to step up its efforts to support individuals in the community would cause a "fundamental alteration" in the state's programs for individuals with disabilities. In arriving at this conclusion, the court noted that Maryland had substantially reduced the number of persons served in its institutions and increased community services. With respect to the plaintiffs, the court noted that the state had tried to arrange community services on their behalf, sometimes successfully but sometimes not. The court decided that ordering the state to step up its efforts would lead to increased expenditures in the short run and thereby affect the state's capacity to serve other individuals. In the court's view, this result would lead to a fundamental alteration and thereby exceed the parameters laid down by the Supreme Court.

<sup>51</sup> A copy of the complaint is located on the previous cited web page.

<sup>52</sup> To obtain this decision, go to [mdd.uscourts.gov/Opinions152/SelectOpsMenu.asp](http://mdd.uscourts.gov/Opinions152/SelectOpsMenu.asp), select "query by case number" and enter CCB-94-880.

#### 7. Massachusetts: Rolland et al. v. Romney et al.

In October 1998, a complaint was filed on behalf of seven Massachusetts residents with mental retardation and other developmental disabilities who were served in nursing facilities. The plaintiffs contended that they were denied alternative community placements or "specialized services" mandated by the federal Nursing Home Reform Amendments enacted in the Omnibus Budget Reconciliation Act of 1987. The law directed that states arrange alternative placements for inappropriately placed residents with developmental disabilities or mental illnesses or, if the person opts to remain in a nursing facility, furnish specialized services that addressed their impairments. The plaintiffs also alleged that the failure to provide such services violated of Title II of the ADA.

In October 1999, the state agreed to offer community residential services and specialized services to nursing home residents with developmental disabilities under the terms of a mediated settlement agreement. The state consented to underwrite community placements to class members (858 individuals) unless it was determined that an individual could not "handle or benefit from a community residential setting." These placements would take place over a multi-year period.

In 2000, the plaintiffs filed a motion asking the court to find the state in violation of the agreement concerning the provision of specialized services to individuals still residing in nursing facilities. In March 2001, the court ruled that the state was required to furnish specialized services sufficient to ensure "active treatment." The court found that, if the services furnished by a nursing facility did not meet the active treatment standard, the Department of Mental Retardation was obliged to furnish supplementary services. In May 2002, the court granted the plaintiffs injunctive relief and ordered that all class members receive services that meet the "active treatment" standard. The state then appealed this ruling to the 1<sup>st</sup> Circuit on 11<sup>th</sup> Amendment sovereign immunity and other grounds.

In January 2003, the Circuit rejected the state's appeal.<sup>53</sup> In a nutshell, the court held that, under federal law, specialized services, including "active treatment" must be furnished to all individuals who need them. The state also had argued that the nursing home reform provisions did not confer a private right to action. The court rejected this argument, holding that the legislation in fact did confer a private right to action, enforceable through the federal courts.

<sup>53</sup> The decision is at [laws.findlaw.com/1st/021697.html](http://laws.findlaw.com/1st/021697.html) and discussed in greater depth in a Bazelon Center for Mental Health Law release ([bazelon.org/newsroom/2-3-03rolland.htm](http://bazelon.org/newsroom/2-3-03rolland.htm).)

### 8. Michigan: Olesky et al. v. Haveman et al.

In September 1999, Michigan's P&A agency filed a complaint in state court on behalf of six individuals with developmental disabilities and/or mental illnesses served in nursing facilities but who wanted services in the community. In June 2000, this litigation was referred to the U.S. District Court for Western Michigan. The plaintiffs' counsel estimated that there were 500 individuals with cognitive disabilities in nursing facilities who could be served in the community. The plaintiffs alleged that Michigan was violating the "Nursing Home Reform Act of 1987" and the ADA. This complaint was similar to *Rolland v. Romney* (see above) except that it included persons with a wider range of cognitive impairments. The Court turned down the state's motion to dismiss the suit on sovereign immunity grounds. The parties then settled. The state agreed to "assure the appropriate and timely community placement of individuals determined to not require nursing facility care. (Priaux, 2004).

### 9. New Jersey: New Jersey Protection & Advocacy v. Davy

In April 2005, New Jersey Protection & Advocacy filed a lawsuit (05-1784) in the U.S. District Court for the District of New Jersey against the Department of Human Services alleging that the state has unnecessarily confined individuals with mental illnesses in state psychiatric hospitals by failing to develop suitable community services to meet their needs. The lawsuit charges the state with violating the ADA and §504, the due process provisions of the U.S. and New Jersey Constitutions, and other provisions of state law.

New Jersey state law provides that individuals committed to state psychiatric hospitals may continue to be held in such facilities even if they do not require inpatient services when community services are not available to meet their needs. Reportedly, more than 40% of 2,300 persons served in state facilities are in continuing placement status due to the lack of community services. The lawsuit charges that New Jersey has failed to develop a comprehensive, effective working plan to provide for the transition of individuals who are unnecessarily confined in state facilities to the community.

### 10. New Jersey: Complaint Citation Not Known

By report, on September 29, 2005, New Jersey Protection and Advocacy filed a complaint in the U.S. District Court for the District of New Jersey alleging that the state is unnecessarily confining individuals with developmental disabilities in its publicly operated state Developmental Centers. At present, 3,100 individuals reside in the centers. State officials have

acknowledged that one-half of these individuals could be supported in the community. The next update to this report will provide more information about this complaint.

### 11. New York: Disability Advocates, Inc. v. Pataki et al.

In July 2003, Disability Advocates, Inc.<sup>54</sup> filed a complaint<sup>55</sup> (03cv03209) in the U.S. District Court for Eastern New York against Governor Pataki, the Department of Health and Office of Mental Health claiming that the placement of individuals with mental illnesses in large "adult homes" violates Title II of the Americans with Disabilities Act and §504 of the Rehabilitation Act by causing their needless institutionalization in substandard facilities when their needs could be more appropriately and effectively met in integrated residential settings. In part, this lawsuit was prompted by the revelations of substandard care in adult homes in a 2002 series of *N.Y. Times* articles.

"Adult homes" are facilities intended to provide room and board, housekeeping, personal care and supervision to residents. The costs of these facilities are underwritten by resident funds, including state SSI supplement payments. Residents of such facilities include individuals with physical disabilities. In New York, there also are a large number of facilities where a high percentage of residents are persons with serious mental illnesses. Facilities are labeled "impacted homes" when 75% or more of the residents have a mental illness. The lawsuit targets 26 such facilities in New York City that have more than 120 beds where an estimated 4,000 persons with mental illnesses reside. Statewide, it is estimated that 12,000 individuals with mental illnesses are served in such facilities. While adult homes nominally provide limited services to residents and are not classified as mental health facilities, residents of these facilities also receive Medicaid-funded health and mental health services from other vendors. The plaintiffs charge that these services do not adequately or appropriately meet the needs of adult care home residents.

The plaintiffs charge that impacted adult homes are segregated institutional settings and as such fall under the purview of the ADA, §504 and the *Olmstead* decision. The plaintiffs point out that New York State also

<sup>54</sup> Disability Advocates, Inc. is an agency under the Protection and Advocacy for Individuals with Mental Illness Act. Co-counsel include New York Lawyers for the Public Interest, Inc., the Bazelon Center for Mental Health Law, MFY Legal Services and Urban Justice Center.

<sup>55</sup> Go to [bazelon.org/issues/disabilityrights/nycomplaint/index.htm](http://bazelon.org/issues/disabilityrights/nycomplaint/index.htm) to view the complaint and obtain additional information.

funds integrated “supported housing” living arrangements that are better geared to meeting the needs of people with serious mental illnesses. However, supported housing is in short supply. Citing studies conducted by the state, the plaintiffs allege that the costs of supporting individuals in supported housing arrangements are no greater than the overall costs of adult care homes (taking into account resident payments and other Medicaid services). Since residents could be served in a more integrated setting, the plaintiffs are asking the court to order the state to expand the availability of supported housing as well as order the state to improve conditions in adult homes.

In October 2003, New York Attorney General Spitzer replied to the complaint, disputing nearly all the allegations made in the complaint. The state argued that the plaintiffs lack standing to bring the complaint and also argued that the plaintiffs who reside in adult homes have not been determined by the state’s treating professionals as appropriate for a more integrated community setting and, thus, do not fall under the ambit of the Olmstead decision. Also, the state argued that the relief sought by the plaintiffs would lead to a fundamental alteration. Next, the state asserted an 11<sup>th</sup> Amendment sovereign immunity defense. Lastly, the state argued that the complaint is barred – in whole or in part – because the alleged violations fell outside the statute of limitations. Therefore, the state urged the court to dismiss the complaint but has not yet filed a formal motion for dismissal. Over the past several months, proceedings have been dominated by disputes concerning discovery issues.

#### **12. New York: William G et al. v. Pataki et al.**

In October 2003, a class action complaint (03-cv-08331) was filed in the United States District Court for Southern New York alleging that New York State is violating Title II of the ADA and §504 of the Rehabilitation Act by failing to furnish treatment services that would permit individuals with serious and persistent mental illnesses who also have a chemical addiction to be released from New York City jails.<sup>56</sup> The plaintiffs allege that they have been discriminated against because other similarly situated individuals who have a chemical addiction but no or minor mental illness are released to community treatment programs more quickly. This complaint was brought on behalf of the plaintiffs by a coalition of organizations, including the Bazelon Center for Mental Health Law, the New York Legal Aid Society and the Urban Justice Center.

<sup>56</sup> The complaint and a discussion of the lawsuit are at: [bazelon.org/newsroom/10-21-03rikers.htm](http://bazelon.org/newsroom/10-21-03rikers.htm).

The plaintiffs are persons charged with violating the conditions of their parole or post-release supervision. Typically, they committed technical parole violations. The complaint alleges that these individuals have been recommended for placement in a residential treatment program in lieu of incarceration. However, a dearth of available community treatment placements causes them to be needlessly incarcerated. The complaint charges that the lack of residential treatment programs results in these individuals languishing in jail, being sent to prison and fated to being trapped in a “vicious cycle between jail and the streets.” The plaintiffs are seeking relief in the form of New York State’s expanding supervised housing programs that serve and treat individuals with co-occurring disorders, either in the form of community residences or supported housing programs. The plaintiffs allege that the costs of needlessly confining these individuals are substantial and the dollars spent on incarceration should be redirected to underwriting community services for them.

In August 2005, the court rejected the state’s motion to dismiss the complaint. In September, the state filed its answer to the complaint, denying all the plaintiffs’ claims.

#### **13. Oregon: Miranda B. et al. v. Kulongoski et al.**

In December 2000, the Oregon Legal Center filed suit (CV-00-01753) in the U.S. District Court for the District of Oregon on behalf of ten state psychiatric institution residents, contending that the state’s own treating professionals had found these individuals to be ready for community discharge but they continued to be institutionalized due to the lack of suitable community placements. The plaintiffs alleged that the state is violating Title II of the ADA, §504 of the Rehabilitation Act and the 14<sup>th</sup> Amendment’s Due Process Clause. In the plaintiffs’ view, this lawsuit revolved around issues analogous to those addressed in the Olmstead decision. The plaintiffs sought class certification.

The state moved for dismissal on various grounds, including 11<sup>th</sup> Amendment sovereign immunity. In September 2001, the court denied the state’s motion for dismissal. The state then appealed to the 9<sup>th</sup> Circuit Court of Appeals (01-35950). In May 2002, the 9<sup>th</sup> Circuit decided to take the appeal. In May 2003, the Circuit rejected the state’s appeal and remanded the case back to the district court for further action.<sup>57</sup>

In December 2003, the parties agreed to settle. In January 2004, the court gave its preliminary approval to the settlement. The agreement applies to the class as

<sup>57</sup> The decision is at: [caselaw.findlaw.com/data2/circs/9th/0135950P.pdf](http://caselaw.findlaw.com/data2/circs/9th/0135950P.pdf).

individuals who were civilly committed to an Oregon psychiatric hospital as of December 1, 2003, had not been discharged within 90-days of a “ready-to-place” determination by a treatment team, and had consented to community treatment. The agreement provides that the state will create 75 new community placements by June 2005 and establish a special \$1.5 million fund to provide supplemental resources to facilitate the placement of individuals who have conditions that are barriers to community reintegration. At least 31 individuals are expected to be placed in the community by June 2005.<sup>58</sup> In March 2004, the court approved the settlement agreement and dismissed the case but retained jurisdiction to enforce compliance with the agreement.

#### **14. Pennsylvania: Frederick L., et al. v. Department of Public Welfare et al.**

In September 2002, the U.S. District Court for Eastern Pennsylvania ruled against the plaintiffs in the Frederick L. v. Department of Public Welfare class action complaint. The plaintiffs are residents of Norristown State Hospital who claim that their continued institutionalization at a state facility – despite recommendations for community placement – violates the ADA and § 504 of the Rehabilitation Act. The Court ruled that the plaintiffs’ circumstances fell within the criteria spelled out in the Olmstead decision. However, the Court decided that accelerating the pace of community placement would lead to increased expenditures and thereby potentially result in reductions in services to other individuals. The Court decided that this would constitute a “fundamental alteration” and thus ruled that it could not grant relief under the ADA. In reaching its decision, the Court relied in part on the decision handed down in the Maryland Wasserman v. Williams litigation (see above).

In October 2002, the plaintiffs appealed this decision to the 3<sup>rd</sup> Circuit of Appeals (02-3721). In December 2002, fourteen former state mental health directors submitted an *amicus* brief on behalf of the plaintiffs.<sup>59</sup> They argued that the district court had adopted too narrow a view concerning the financial implications of accelerated community placement by failing to take into account the potential to offset costs by employing Medicaid funds to hold down the state’s costs of supporting individuals in the community. They pointed out that the hospital was funded with state dollars (federal law prohibits Medicaid funding of “Institutions for Mental Disease”) but Medicaid funding could

be used to underwrite the costs of community services. The Circuit heard oral arguments in October 2003.

In April 2004, the Circuit Court handed down its opinion.<sup>60</sup> In what it characterized as a “precedential” opinion, the court vacated the district court’s judgment and remanded the case back to the district for further proceedings. The Circuit Court decided that, in order to establish a “fundamental alteration” defense under Olmstead, a state had to demonstrate that it had a comprehensive working plan in effect to assure that going forward individuals would be served in the most integrated setting. The Court expressed the view that budgetary and cost considerations alone were an insufficient to support a fundamental alteration defense. While acknowledging Pennsylvania’s prior efforts to reduce reliance on institutional settings and expand community services, the court pointed out that “past progress is not necessarily probative of future plans to continue deinstitutionalizing.” The court observed:

“After all, what is at issue is compliance with two federal statutes enacted to protect disabled persons. The courts have held states throughout the country responsible for finding the manner to integrate schools, improve prison conditions, and equalize funding to schools within the respective states, notwithstanding the states’ protestations about the cost of remedial actions. The plaintiffs in this case are perhaps the most vulnerable. It is gross injustice to keep these disabled persons in an institution notwithstanding the agreement of all relevant parties that they no longer require institutionalization. We must reflect that on that more than a passing moment. It is not enough for DPW to give passing acknowledgment of that fact. It must be prepared to make a commitment to action in a manner for which it can be held accountable by the courts.”

While not disagreeing with many of the findings made by the district court, the Circuit directed the district court to request Pennsylvania to make “a submission that the district court can evaluate to determine whether it complies with this opinion.”

In September 2004, the District Court entered a judgment in favor of the state and dismissed the case.<sup>61</sup> The court found that the state’s deinstitutionalization plan and planning process “deserve the protection of the fundamental alteration defense.” The court rejected the plaintiffs’ contention that the state’s plans were not sufficiently concrete. The plaintiffs have appealed this judgment to the 3<sup>rd</sup> Circuit (04-3859). The Circuit Court heard oral arguments in July 2005.

<sup>58</sup> The agreement is described in more detail in the Oregon Advocacy Center’s newsletter, available at: [oradvocacy.org/staff/newslet/OAC2004Winter.pdf](http://oradvocacy.org/staff/newslet/OAC2004Winter.pdf).

<sup>59</sup> The brief is at: [centerforpublicrep.org/page/94546](http://centerforpublicrep.org/page/94546)

<sup>60</sup> The opinion is available at: [caselaw.lp.findlaw.com/data2/circs/3rd/023721p.pdf](http://caselaw.lp.findlaw.com/data2/circs/3rd/023721p.pdf).

<sup>61</sup> This decision is available at: [paed.uscourts.gov/documents/opinions/04D0294P.pdf](http://paed.uscourts.gov/documents/opinions/04D0294P.pdf)

In September 2005, the Circuit Court handed down its ruling.<sup>62</sup> It decided that the district court had erred in dismissing the complaint because the state's integration plan was not sufficiently concrete to establish a fundamental alteration defense. The court found that the plan lacked measurable benchmarks, noting that a "viable integration plan at a bare minimum should specify the time-frame or target date for patient discharge, the approximate number of patients to be discharged each time period, the eligibility for discharge, and a general description of the collaboration required between the local authorities and the housing, transportation, care, and education agencies to effectuate integration into the community." The court remanded the complaint to the district court for further proceedings.

### **15. Pennsylvania: Pennsylvania Protection & Advocacy v. Dept. of Public Welfare et al.**

In September 2000, Pennsylvania Protection and Advocacy (PPA) filed suit (CV-00-1582) in the U.S. District Court for Middle Pennsylvania on behalf of the residents of South Mountain Restoration Center (SMRC), a state-operated nursing facility that serves elderly individuals who have severe mental disabilities, many of whom have experienced long-term institutionalization. PPA contended that SMRC residents could be served in more integrated community settings and, hence, their continued institutionalization violated both Title II of the ADA and §504 of the Rehabilitation Act. PPA petitioned the court to appoint an independent expert to identify SMRC residents who could be placed in the community and direct the Department of Public Welfare to commence a program of community placement.

In January 2003, the court ruled in the state's favor and dismissed the lawsuit. In its ruling, the court noted that both parties agreed that many SMRC residents could be served in the community. The state, however, argued that the costs involved in serving these individuals in the community would require a "fundamental alteration" in its programs for persons with mental disabilities because community placement would lead to net increased spending and, thereby, require shifting dollars from services provided to other individuals with mental disabilities to accommodate the placement of SMRC residents.

The court was swayed by the testimony of a defense expert who calculated that the average costs of community placement would exceed average costs at SMRC and, further, that costs of community placement would not be completely offset by reduced

expenditures at SMRC. Based on its reading of the Olmstead decision, the court decided that the predicted increase in expenditures necessary to pay for community placements but continue to operate SMRC, in fact, would cause a fundamental alteration. PPA had urged the court to take a broader view of the fundamental alteration question by considering not only the budget for services for persons with mental disabilities but also take into account the overall state budget and other spending within the Department of Public Welfare. The Court rejected this approach, again relying on its interpretation of the Olmstead decision that it should confine itself to the effects on the dollars allocated for services for persons with mental disabilities.

In February 2003, PPA appealed the decision to the 3<sup>rd</sup> Circuit (03-1461). In November 2003, the Circuit Court agreed to a PPA request to hold this appeal in abeyance pending the outcome of the Frederick L appeal (see above). Following the decision in the Frederick L appeal, the court lifted the stay on proceedings. PPA then filed its appellant brief in June 2004. Oral arguments were heard in October 2004.

In March 2005, the Circuit Court handed down its decision.<sup>63</sup> The court ruled that the district court's dismissal of the lawsuit solely based on the state's fundamental alteration defense "lacks sufficient underpinning." Following much the same reasoning it followed in its Frederick L decision, the Circuit ruled that the fundamental alteration defense requires more evidence than the state had presented and that the state had not demonstrated a "commitment to action" to bring the facility into compliance with the ADA and the Rehabilitation Act. As a result, the court vacated the court's grant of summary judgment in favor of the state, ordered the district court to enter summary judgment in favor of the plaintiffs with respect to the "legal insufficiency of the [state's] fundamental alteration defense," and remanded the case back to the district court for further proceedings. There have been no proceedings at the district court since the remand.

### **16. Other Litigation**

Other litigation in this arena has included lawsuits concerning individuals who have a mental illness who are served in state mental health facilities. Some of these lawsuits include the Charles Q v. Houston and Kathleen S v. Department of Public Welfare litigation in Pennsylvania as well as certain California lawsuits. Also in Pennsylvania, the Helen L. v. Dedario litigation raised "Olmstead"-like issues: namely, the access

<sup>62</sup> Located at [ca3.uscourts.gov/opinarch/043859p.pdf](http://ca3.uscourts.gov/opinarch/043859p.pdf)

<sup>63</sup> Located at: [caselaw.lp.findlaw.com/data2/circs/3rd/031461p.pdf](http://caselaw.lp.findlaw.com/data2/circs/3rd/031461p.pdf)

of nursing facility residents to community waiver services (specifically personal assistance/ attendant care). In 1995, the 3<sup>rd</sup> Circuit Court of Appeals held that the state's failure to provide services in the most integrated setting appropriate to a person's needs violated the ADA.<sup>64</sup> Additionally, the Court held that the provision of waiver services to the plaintiff would not fundamentally alter the nature of the waiver program because the services the plaintiff needed were already provided in the waiver program.

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<sup>64</sup> This decision is at: [ahcuah.com/lawsuit/federal/didario](http://ahcuah.com/lawsuit/federal/didario).

## IV. Limitations on Medicaid Home and Community Services

### A. Overview

“Access to benefits” lawsuits revolve around whether Medicaid beneficiaries can obtain services and supports that they have been approved or are entitled to receive. Litigation in this arena includes lawsuits that argue that low state payment rates prevent beneficiaries from finding a personal assistant or other workers to provide needed services. The Medicaid statutory issues concerning the interplay among payments, adequacy, quality, and access to benefits/services are discussed in detail in a National Health Law Project paper.<sup>65</sup> There have been many cases where the availability and quality of services available through the Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefits for children with disabilities has been at issue.<sup>66</sup>

These lawsuits contend that state policies or practices concerning the operation of community programs constitute barriers to individuals obtaining authorized services. In some cases, these barriers are alleged to violate the ADA, either because they force individuals to accept institutional services due to a shortage of community services while there is more generous state funding for institutional services, thereby discriminating against people who want community services. In the Arizona and California lawsuits, the plaintiffs also allege that state’s funding practices violate §1902(a)(30)(A) of the Social Security Act, which requires states to make payments for Medicaid services sufficient to ensure their availability to Medicaid beneficiaries. In particular, §1902(a)(30)(A) provides that the “State plan for medical assistance must ... provide such methods and procedures relating to the ... the payment for care and services under the plan ... as may be necessary ... to assure that payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are

available to the general population in the geographic area.” HCBS waiver programs are not exempt from §1902(a)(30)(A).

As in other dimensions of Medicaid law, issues have arisen concerning whether §1902(a)(30)(A) confers enforceable rights. As discussed below, the district court found in the *Sanchez v. Johnson* litigation that this provision is not enforceable through a §1983 action and dismissed the lawsuit. That decision is now on appeal to the 9<sup>th</sup> Circuit as is the decision in another California case (*Clayworth*) where a different district found that §1902(a)(30)(A) is enforceable. In March 2004, the 1<sup>st</sup> Circuit Court of Appeals handed down a ruling that §1902(a)(30)(A) is not enforceable, based on the U.S. Supreme Court *Gonzaga* decision.<sup>67</sup> This ruling is noteworthy because the 1<sup>st</sup> Circuit abandoned its previous position that §1902(a)(30)(A) was enforceable and in light of its other post-Gonzaga decisions upholding the enforceability of various other provisions of Medicaid law. Clearly, this dimension of Medicaid law is very unsettled.

### B. Description of Lawsuits

#### 1. Arizona: *Ball et al v. Biedess et al.*

In January 2000, the Arizona Center on Disability Law and the Native American Protection and Advocacy Agency filed a class-action complaint (00-cv-67) in the U. S. District Court for Arizona arguing that Medicaid payment rates for direct service professionals (attendants) in the community are insufficient to attract enough providers to ensure that Medicaid services are available to persons with disabilities.<sup>68</sup> Among its other claims, the lawsuit argues that the state is violating §1902(a)(30)(A) by failing to make payments sufficient to attract enough providers to meet the needs of Medicaid recipients. The plaintiffs also claim that the state also is violating other Medicaid requirements, including: 1) reasonable promptness; 2) amount, duration and scope; and, 3) freedom of choice. Also, the plaintiffs argue that Arizona violates Title II of the ADA and §504 of the Rehabilitation Act because the lack of sufficient community support workers puts individuals with disabilities at risk of institutionalization. The District Court granted class certification. The bench trial was conducted in October 2003.

<sup>65</sup> Located at: [healthlaw.org/docs/200009IssueBriefHCBC.pdf](http://healthlaw.org/docs/200009IssueBriefHCBC.pdf)

<sup>66</sup> EPSDT benefits are described in: Sarah Knipper (2004): *EPSDT: Supporting Children with Disabilities* available at: [hsri.org/docs/792FinalEPSDTBooklet.PDF](http://hsri.org/docs/792FinalEPSDTBooklet.PDF). There has been a high volume of litigation in the arena of EPSDT benefits. There is considerable information about this litigation at [healthlaw.org/children.shtml#EPSDT](http://healthlaw.org/children.shtml#EPSDT). The National Health Law Project has released a very useful paper (*Fact Sheet: Medicaid Early and Periodic Screening, Diagnosis and Treatment: Recent Case Developments* – available at: [healthlaw.org/pubs/200402.EPSDT.cases.pdf](http://healthlaw.org/pubs/200402.EPSDT.cases.pdf)) that describes many of important cases that concerning EPSDT and discusses trends in how courts have decided these cases.

<sup>67</sup> This ruling concerned the Massachusetts Long Term Care Pharmacy Alliance v. Ferguson lawsuit. The ruling is available at: [laws.findlaw.com/1st/031895.html](http://laws.findlaw.com/1st/031895.html) and is described in an article at: [healthlaw.org/pubs/200403.firstcircuit.html](http://healthlaw.org/pubs/200403.firstcircuit.html).

<sup>68</sup> The complaint and related materials can be found at: [acdl.com/ball.html](http://acdl.com/ball.html).

In August 2004, the court ruled in favor of the plaintiffs, finding that Arizona violated §1902(a)(30)(A) by not providing enough attendants to meet the needs of Medicaid beneficiaries.<sup>69</sup> Specifically, the court found that Arizona's payments were insufficient to assure "equal access" and "quality of care." The court ordered that the state: must provide each beneficiary attendant care "without gaps in service" and offer a rate of pay that is sufficient to "attract enough health care workers to deliver all of the services for which the individual qualifies." However, the court stopped short of specifying the amount that the state must pay. The court also ordered the state to make additional improvements in its program. The court ordered the parties to file schedules to carry out the directives contained in its order by September 30, 2004.

In late August 2004, the state moved to request a new trial and asked for a stay of the district court's order, pending the disposition of its appeal of the decision to the 9<sup>th</sup> Circuit. In September, the state filed its appeal (04-16963). In May 2005, the Circuit Court denied the state's request to stay the district court's order but has agreed to hear the appeal.

## **2. Arkansas: Pediatric Specialty Care, Inc. et al. v. Arkansas Department of Human Services et al.**

In November 2001, the Arkansas Department of Human Services (ADHS) announced plans to cut back Medicaid benefits due to budget shortfalls. Among other actions, ADHS proposed eliminating distinct state plan coverage of early intervention day treatment and therapy furnished to children with developmental disabilities ages 0-6. These services are furnished as part of the state's Child Health Management Services (CMHS) program by specialized providers. Three of these providers and three affected families filed suit in the U.S. District Court for Eastern Arkansas to enjoin ADHS against eliminating these early intervention services. In December 2001, the district court granted a permanent injunction debarring ADHS from removing the listing of these services from the state plan, reasoning that the federal requirements concerning Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandated that these services be provided so long as they had been ordered by a physician and would result in the "maximum reduction of medical and physical disabilities and restoration of the child to his or her best functional level." State officials argued that they had the "legal right to decide whether to include the services" in the state's Medicaid program. They also contended that the

services would continue to be available, although not in the form of a distinct program.

ADHS appealed the injunction to the 8<sup>th</sup> Circuit. In June 2002, the Circuit ruled that Medicaid-eligible children have a right to early intervention services and that ADHS "must pay part or all of the cost of treatment discovered by doctors who first diagnose and evaluate the children."<sup>70</sup> The Circuit decided that federal law does not require ADHS to specifically identify the services at issue in its Medicaid state plan. However, so long as the services are determined as necessary by a physician, it must pay for them since federal law mandates that Medicaid-eligible children receive physician-ordered services whether the state has formerly listed them or not. The Circuit also reminded "the state that it has a duty under §1902(a)(43) of the Social Security Act] to inform recipients about the EPSDT services that are available to them and that it must arrange for the corrective treatments prescribed by physicians. The state may not shirk its responsibilities to Medicaid recipients by burying information about available services in a complex bureaucratic scheme." The Court remanded the case to the district court to revise the injunction and consider the remaining plaintiff claims.

In November 2002, the district court issued a new order. The thrust of this order was to continue a revised injunction to compel the state to continue to furnish the disputed services. In his order, Judge Wilson expressed chagrin concerning state actions, which in his view were attempts to end-run the injunction. The state then filed a motion asking for a modification of the order, arguing that it had secured federal approval for a Medicaid state plan amendment that complied with the 8<sup>th</sup> Circuit decision and the effect of the new order might be that the state would not receive federal Medicaid funds for day treatment services under the amended state plan. The plaintiffs countered, arguing that the change in the Medicaid plan coupled with other state actions would have the effect of sharply reducing access to the services or putting new obstacles in the way of families' obtaining the services. The plaintiffs also asked that the Court to review changes that the state might propose in the future to ensure that they would not eliminate the disputed services.

In December 2002, the district court modified its order, finding that the latest order was not inconsistent with the 8<sup>th</sup> Circuit ruling. The court continued the injunction directing the state to continue to provide the services and also applied the order to the federal

<sup>69</sup> The decision also is located at: [acdl.com/ball.html](http://acdl.com/ball.html).

<sup>70</sup> Located at: [caselaw.lp.findlaw.com/data2/circs/8th/013971p.pdf](http://caselaw.lp.findlaw.com/data2/circs/8th/013971p.pdf)

Centers for Medicare and Medicaid Services (CMS) and ordered CMS to continue to provide federal Medicaid funding for the services. But, the court declined to directly supervise the state's administration of these services, again enjoined the state to continue to provide and pay for early intervention and related services and barred the state from implementing changes in the provision of these services. In part, the court based its injunction on the provisions of §1902(a)(30)(A) of the Social Security Act, reasoning that the changes that the state had in mind would affect access to services and that the implementation of any changes had to be preceded by a study to determine their impact.

ADHS appealed the revised order to the 8<sup>th</sup> Circuit; CMS filed its own appeal concerning the order. In its appeal, ADHS protested that its removal of the distinct state plan coverage of early intervention services did not in any way mean that children could not obtain them. CMS concurred and also argued that the district court's order was improper on a number of grounds. The plaintiffs have countered that ADHS is engaged in an ongoing effort to "deconstruct" the services that they furnish. The Circuit Court heard oral arguments in January 2004.

In April 2004, the 8<sup>th</sup> Circuit ruled on the appeal.<sup>71</sup> It dismissed CMS as a party to the litigation. It upheld the district court's injunction on procedural due process grounds, concluding that the injunction against the state's making changes in its program was proper "until a full impact study on the effect of terminating the [CMHS] program is completed."

In July 2004, a fourth amended complaint was filed. This complaint alleges that a prior authorization system that ADHS implemented for CMHS has been operated to arbitrarily deny necessary services to children in order to cut state expenditures. The revised complaint names the Arkansas Foundation for Medical Care (the state's Professional Review Organization (PRO)) as a defendant because it operates the prior authorization system. The state moved to dismiss this complaint, arguing that it had the authority to determine the medical necessity of CMHS. In February 2005, the court rejected the state's motion, concluding that the plaintiffs had established a sufficient basis to proceed to trial to determine whether the prior authorization system resulted in the impermissible denial of

services to children. In March, the state appealed this ruling to the 8<sup>th</sup> Circuit (05-1668).<sup>72</sup>

### 3. California: Sanchez et al. v. Johnson et al.

Filed in May 2000 in the U.S. District Court for Northern California on behalf of individuals with developmental disabilities, this complaint (00cv01593) alleges that California has "established and maintained highly differential payment and wage and benefit structures between the institutional and community-based components of California's developmental disability services program, which has the effect of subjecting people with developmental disabilities to unnecessary institutionalization and segregation."<sup>73</sup> The plaintiffs – persons with disabilities, provider and advocacy organizations – claim the state, in creating payment differentials, violates Title II of the ADA, both with respect to the integration mandate and other regulations "prohibiting a public entity from providing different or separate aids, benefits or services to individuals with disabilities of to any class of individuals with disabilities that is provided to others." Additionally, the plaintiffs point out that ADA regulations prohibit public entities from "utilizing criteria or methods of administration ... that have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability." As a result, they allege that California has discriminated against the plaintiffs by "utilizing criteria and methods of administration that discriminate against people with disabilities by [offering] low wages for direct care and professional staff."

Claims based on Medicaid law include the allegation that state payments for community services are insufficient to assure efficiency, economy, and quality of care and enlist sufficient qualified providers to ensure access to services as required by §1902(a)(30)(A). The plaintiffs petitioned the court to order the state to improve its community services payment and benefit structure and correct other problems that are alleged to lead to unnecessary institutionalization.

In August 2001, the Court certified the lawsuit as a class action.<sup>74</sup> In September 2001, the Court rejected the state's motion for partial summary judgment to dismiss the plaintiffs' claims with respect to §1902(a)(30)(A). The state argued that neither people

<sup>71</sup> This ruling is located at: [caselaw.lp.findlaw.com/data2/circs/8th/031015p.pdf](http://caselaw.lp.findlaw.com/data2/circs/8th/031015p.pdf).

<sup>72</sup> A recap of this litigation's history is located at: [healthlaw.org/pubs/200504.Q&A.PedSpecCare.pdf](http://healthlaw.org/pubs/200504.Q&A.PedSpecCare.pdf)

<sup>73</sup> This complaint may be found at [sanchezvsjohnson.org/lawsuit.html](http://sanchezvsjohnson.org/lawsuit.html). Other materials are found at [sanchezvsjohnson.org/updates.html](http://sanchezvsjohnson.org/updates.html).

<sup>74</sup> The Court's class certification order is at [sanchezvsjohnson.org/order1593.html](http://sanchezvsjohnson.org/order1593.html).

with disabilities nor providers may bring a lawsuit in federal court to enforce these provisions. In March 2002, the plaintiffs filed a motion for summary judgment.<sup>75</sup> The motion for summary judgment asked the court to issue “an order enjoining defendants at least to double current community direct care wages and benefits, making them substantially equal to institutional direct care wages and benefits and index them to meet defendants’ future, continuing duties under federal statutes.”

In August 2002, District Court Judge Claudia Wilken turned down the plaintiffs’ motion for summary judgment but ruled that the issues raised by the plaintiffs did not constitute violations of the ADA or §504 of the Rehabilitation Act.<sup>76</sup> Judge Wilken also denied the state’s motion to dismiss the case on sovereign immunity grounds. She then ordered that the case proceed to trial. The remaining trial issues concerned whether California’s payments are sufficient to enable providers to furnish quality services and individuals to be able to access to necessary services, as required by §1902(a)(30)(A).

In August 2003, the state filed a motion asking the court to reconsider its decision that the plaintiffs could seek relief in federal court for the alleged violations of Medicaid law. In its motion, the state argued that, in light of the *Gonzaga* decision, the court should conclude that neither individuals nor providers have enforceable rights under the Medicaid Act. Also, the state filed proposed findings of law and fact. In its proposed findings of law, the state implicitly urged the court to find that its policies and practices in fact had not violated §1902(a)(30)(A).

In January 2004, Judge Wilken dismissed the lawsuit. She agreed with the state’s argument that the federal Medicaid Act does not confer individually enforceable rights but instead has an aggregate focus. She based her decision on her application of the U.S. Supreme Court’s *Gonzaga* decision to the provisions of §1902(a)(30)(A) and decisions in other cases (including the Pennsylvania *Sabree* decision and another Northern District lawsuit concerning the application of §1902(a)(30)(A) (*California Association of Health Facilities v. State Department of Health Services* (03-736)).

Characterizing Judge Wilken’s decision as “fatally

<sup>75</sup> This motion is located at [sanchezvsjohnson.org/summary.html](http://sanchezvsjohnson.org/summary.html).

<sup>76</sup> Marty Omoto, Legislative Director, California UCP (August 9, 2002). “CA UCP Legal Update: Sanchez v. Johnson Case: Federal District Court Orders Case to Trial; Judge Denies Plaintiffs’ Summary Judgment Motion, Ruling Partially in Favor of State.”

flawed,” the plaintiffs appealed the dismissal to the 9<sup>th</sup> Circuit in early February 2004 (04-15228). The plaintiffs expect to rely on a December 2003 U.S. District Court for Eastern California decision in lawsuits<sup>77</sup> that also concerned Medicaid payments. In that litigation, the district court also wrestled the implications of the *Gonzaga* decision concerning whether §1902(a)(30)(A) conferred individually enforceable rights for which Medicaid recipients and providers could seek federal court intervention under §1983. Based on its reading of legislative history, the court decided that Congress intended to confer individually enforceable rights under §1902(a)(30)(A) for beneficiaries but not Medicaid providers. Based on this conclusion and other 9<sup>th</sup> Circuit decisions, the court then granted the plaintiffs a preliminary injunction that prevented California from implementing Medicaid rate cuts that were slated to go into effect January 1, 2004.<sup>78</sup> The *Sanchez* plaintiffs filed their appellant brief in May 2004. The Court heard oral arguments in the *Sanchez, Clayworth and CMA* appeals in December 2004.

In August 2005, the 9<sup>th</sup> Circuit upheld the district court decision dismissing the *Sanchez* complaint.<sup>79</sup> The court decided that §1902(a)(30)(A) did not confer individually enforceable rights for either providers or Medicaid beneficiaries, applying the tests that the U.S. Supreme Court had set out in its *Gonzaga* decision. The court concluded that §1902(a)(30)(A) does “not focus on an individual recipient’s or provider’s right to benefits, nor is the ‘broad and diffuse’ language of the statute amenable to judicial remedy. We conclude, therefore, that Congress has not spoken with an unam-

<sup>77</sup> The lawsuits are: *Clayworth et al. v. Bonta et al.* (03-2110) and *California Medical Association et al. v. Bonta et al.* (03-2336). Both of these lawsuits were filed to prevent California from instituting a 5% across the board rate reduction in Medicaid (Medi-Cal) payments as part of the state’s efforts to cut its budget deficit. The state appealed both decisions to the 9<sup>th</sup> Circuit (04-15498 and 04-15532), which has consolidated the appeals.

<sup>78</sup> This decision is located at: [207.41.18.73/caed/DOCUMENTS/Opinions/Levi/03-2110.pdf](http://207.41.18.73/caed/DOCUMENTS/Opinions/Levi/03-2110.pdf). In the decision, the court noted that interpreting the legislative history surrounding §1902(a)(30)(A) posed some difficulties. Once the court decided that Medicaid beneficiaries could bring a federal action to block rate cuts that might harm them, it relied on the standards set down by the 9<sup>th</sup> Circuit in its 1997 *Orthopaedic Hospital v. Belshe* decision (located at: [laws.findlaw.com/9th/9555607.html](http://laws.findlaw.com/9th/9555607.html)) in deciding that the state’s rate cut was improper.

<sup>79</sup> This decision may be found at: [ca9.uscourts.gov/ca9/newopinions.nsf/3A95CF272053DC6E882570510054C594/\\$file/0415228.pdf?openelement](http://ca9.uscourts.gov/ca9/newopinions.nsf/3A95CF272053DC6E882570510054C594/$file/0415228.pdf?openelement). The court also reversed the district court’s rulings in the *Clayworth and CMA* complaints.

biguous, clear voice that would put a State on notice that Medicaid recipients or providers are able to compel state action under §1983.” The court also upheld the district court’s ruling throwing out the ADA claim, agreeing that the state had made progress in deinstitutionalizing individuals and that ordering an increase in payments would cause the state to make fundamental alterations.

The Sanchez plaintiffs have petitioned for *en banc* review of the decision.<sup>80</sup> To date, the Circuit Court has not acted on this petition.

#### 4. California: Rodde et al. v. Bonta et al.

This lawsuit (03-01580) was filed in the U.S. District Court for the District of Central California expressly to halt Los Angeles County’s plan to close Rancho Los Amigos National Rehabilitation Center, a county-operated facility that furnishes specialized inpatient and outpatient services to individuals with disabilities. The plaintiffs sought and obtained from the court a preliminary injunction to halt the closure, contending that, if the facility were closed, they would be left without access to medically necessary services. The plaintiffs based their claims on federal Medicaid law (arguing that they would be unable to obtain services covered by California’s Medicaid program) and the ADA (arguing that the county’s action was discriminatory because it treated people with disabilities differently than other Medicaid recipients who did not face a similar loss of access to services). The county appealed the injunction to the 9<sup>th</sup> Circuit Court of Appeals (03-55765).

In February 2004, the Circuit upheld the preliminary injunction, concluding that the plaintiffs were likely to succeed on the merits of their ADA claim.<sup>81</sup> The court agreed that, absent the injunction, the plaintiffs faced potential harm. The Circuit also noted that the district court decision did not mean that the county could not ultimately close the facility but, instead, if it were to close the facility, it had to ensure that comparable services would be available to the plaintiffs.

#### 5. Connecticut: Pragano et al. v. Wilson-Coker

In November 2002, three Medicaid beneficiaries with disabilities filed a lawsuit (02-CV-1968) against the Connecticut Department of Social Services (DSS, the state’s Medicaid agency) alleging that the state was refusing to pay for durable medical equipment they need to improve their health and live independently. The plaintiffs argue that the state has adopted “an un-

written and unpublished policy of denying Medicaid payment for any equipment not covered by the federal Medicare program,” thereby impermissibly restricting access to necessary equipment. The plaintiffs sought a preliminary injunction and class certification. The plaintiffs are represented by New Haven Legal Assistance Association and Connecticut Legal Services.

In 1997, the New Haven Legal Assistance Association filed a similar lawsuit (*DeSario v. Thomas*) challenging Connecticut’s practice of limiting payment for medical equipment to items included on a list established by DSS. Ultimately, this case was settled by the state’s agreeing to periodically update its list of covered items and allow individuals to obtain unlisted items when necessary. This litigation also prompted the Health Care Financing Administration (now CMS) to clarify its policies concerning the coverage of medical equipment, including requiring states to provide individuals “a meaningful opportunity for seeking modifications of or exceptions to a State’s pre-approved list.” This policy was promulgated via a September 1998 State Medicaid Director letter.<sup>82</sup>

In this lawsuit, the plaintiffs alleged that the Department was once again employing an arbitrary list to deny individuals of equipment that is necessary for them to function in the community and thereby increase their risk of institutionalization. In particular, the plaintiffs alleged that Connecticut’s policies violated: (a) §1902(a)(17)(A) of the Social Security Act which requires that the state apply reasonable standards in determining eligibility for services; (b) the goals of the Medicaid by denying payment for DME necessary for individuals to attain and maintain independence and self-care; and, (c) Medicaid requirements that bar limiting the scope of coverage based on a person’s specific medical condition. In March 2003, the Court turned down the plaintiffs’ request for a preliminary injunction. The parties arrived at a tentative settlement in September 2003. In December 2003, the court approved the agreement. Under the agreement, the Department of Social Services has issued a revised provider bulletin concerning DME and beneficiary rights to appeal adverse determinations.

#### 6. Illinois: Jackson et al. v. Maram

In January 2004, three individuals residents filed a class action complaint (04-0174) against the Illinois Department of Public Aid in the U.S. District Court for the Northern Illinois contending that the agency impermissibly denies motorized wheelchairs to nursing facility residents in violation of federal Medicaid law, the ADA and §504 of the Rehabilitation

<sup>80</sup> The Clayworth and CMA plaintiffs also have petitioned for *en banc* review.

<sup>81</sup> Decision located at: [caselaw.lp.findlaw.com/data2/circs/9th/0355765p.pdf](http://caselaw.lp.findlaw.com/data2/circs/9th/0355765p.pdf)

<sup>82</sup> Located at: [cms.hhs.gov/states/letters/smd90498.asp](http://cms.hhs.gov/states/letters/smd90498.asp)

Act. The plaintiffs have been denied motorized wheelchairs even though rehabilitation hospitals have determined that the plaintiffs would benefit from them. As a consequence, the plaintiffs contend that they are unnecessarily confined to the nursing homes in which they reside. In contrast, the plaintiffs point out that individuals who are not in nursing facilities are authorized to receive Medicaid-funded motorized wheelchairs. The lawsuit was filed on the plaintiffs' behalf by Access Living of Metropolitan Chicago, an Independent Living Center.

The plaintiffs contend that the state's policy to not provide motorized wheelchairs to nursing home residents violates the requirements of the federal 1987 Nursing Home Reform Act, §1902(a)(10)(B) by not making Medicaid services available to all beneficiaries who require them, the ADA (by virtue of discriminatory treatment of individuals with disabilities and encouraging unnecessary segregation of nursing facility residents), and §504 because the state's policies discriminate on the basis of disability.

The state moved to dismiss and in opposition to class certification. Both motions adopted the position that Medicaid law, the ADA, and the Rehabilitation Act do not give the plaintiffs enforceable rights that may be pursued through a §1983 action. In August 2004, the court granted the motion for class certification.<sup>83</sup> Court proceedings are suspended for the time being to permit the parties to explore the potential for settlement.

#### 7. Illinois: Bertrand et al. v. Maram et al.

Filed in January 2005 in the U.S. District Court for the Northern District of Illinois, this lawsuit (05-0544) charges that Illinois impermissibly restricts the access to Community-Integrated Living Arrangement (CILA) residential services in its HCBS waiver program for persons with developmental disabilities. This is a class action complaint. It follows on the heels of a non-class action complaint (*Drzewicki v. Maram et al.* (04-CV-7164) that raised the same issue but which the state agreed to settle.

Like the predecessor complaint, this lawsuit contends that Illinois is violating the reasonable promptness requirement at §1902(a)(8) of the Social Security Act and is at odds with the policies set forth in CMS Olmstead Letter #4, which provides that a state may not deny covered waiver services to waiver participants who require them. In particular, the plaintiffs contend that Illinois' policy of limiting the availability of CILA services to persons who satisfy the state's

emergency or priority placement criteria is an impermissible limitation on access to services.

In February 2005, the state answered the complaint. The state argued that Medicaid law does not confer individually enforceable rights and, consequently, the plaintiffs do not have standing to bring an action in federal court. The state also advanced the defense that the criteria it uses to regulate access to CILA services were contained in its waiver application to CMS and, because CMS had approved the application, the criteria were allowable.

Both the plaintiffs and the state have filed motions for summary judgment. The state also has filed a motion opposing class certification.

#### 8. Indiana: Collins et al. v. Hamilton et al.

In 2001, the Indiana Civil Liberties Union filed a class action lawsuit against state officials for failing to provide child and youth long-term residential treatment in psychiatric residential treatment facilities (PRTF). The plaintiffs argued that Indiana's refusal to provide such services violated federal Medicaid law because PRTF services are a recognized Medicaid benefit and, hence, must be furnished to all eligible children and youth when "medically necessary" under the federal Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandate. The district court ruled in plaintiffs favor, deciding that the provision of PRTF services was mandatory when medically necessary. The court permanently enjoined Indiana from denying these services.

In 2002, the state appealed this decision to the 7<sup>th</sup> Circuit Court of Appeals (02-3935), arguing that it had decided to exclude such services for various reasons. In November 2003, the Circuit Court rejected the state's appeal and upheld the district court decision.<sup>84</sup> The court found that the EPSDT mandate requires that a state must furnish any Medicaid coverable service that is medically necessary.

#### 9. Kansas: Interhab, Inc. et al. v. Schalansky et al.

In October 2002, Interhab and five other community service providers filed a class action lawsuit in Shawnee County District Court (02C001335) against the Kansas Department of Social and Rehabilitation Services (SRS) claiming that the state's payments are insufficient to meet the needs of people with developmental disabilities and thereby violate Kansas and federal law. Interhab is an association of Kansas community service providers. The plaintiffs assert that com-

<sup>83</sup> [equipforequality.org/news/equalizer/06legallhighlights.php](http://equipforequality.org/news/equalizer/06legallhighlights.php)

<sup>84</sup> The decision is at: <http://caselaw.findlaw.com/data2/circs/7th/023935P.pdf>

munity services were underfunded by \$88 million. The lawsuit also seeks damages for alleged underfunding in previous years; such damages might total \$300 million, according to the plaintiffs.

The lawsuit claims that the state has violated the state's 1996 Developmental Disabilities Reform Act (DDRA), which the plaintiffs argue mandates that the state provide "adequate and reasonable" funding for community services. In particular, the plaintiffs point out that the DDRA made it Kansas policy that:

"...this state ...assist persons who have a developmental disability to have: (a) Services and supports which allow persons opportunities of choice to increase their independence and productivity and integration and inclusion into the community; (b) access to a range of services and supports appropriate to such persons; and (c) the same dignity and respect as persons who do not have a developmental disability." (K.S.A. 39-1802).

The DDRA also provides that SRS establish "a system of adequate and reasonable funding or reimbursement for the delivery of community services that:

"requires an independent, professional review of the rate structures on a biennial basis resulting in a recommendation to the legislature regarding rate adjustments. Such recommendations shall be adequate to support: (A) a system of employee compensation competitive with local conditions; (B) training and technical support to attract and retain qualified employees; (C) a quality assurance process which is responsive to consumers' needs and which maintains the standards of quality service (D) risk management and insurance costs; and (E) program management and coordination responsibilities." (K.S.A. 39-1806)

The plaintiffs charge that the required rate review was not conducted and the wage rates upon which SRS bases payments are inadequate. As a result, provider agencies are unable to recruit and retain qualified staff to meet the needs of individuals. In addition to violating the DDRA, the plaintiffs also charge that SRS has violated §1902(a)(30)(A) of the Social Security Act by not making payments sufficient to ensure that "consumers of community programs and services have access to high quality care." The plaintiffs also are advancing an equal protection claim under both the U.S. and Kansas Constitutions by contending that the state discriminates between community providers and its own institutions by funding similar services differently. The plaintiffs also allege breach of contract.

The plaintiffs are asking the court to: (a) review all payment rates for the period 1996 – 2003; (b) order the state to pay for all "underfunding" during that period; (c) enjoin the state to pay "adequate and reasonable

reimbursement rates"; (d) enjoin the state to establish a rate setting methodology that complies with federal and state law; and (e) enter a judgment directing SRS to reimburse all costs incurred by the plaintiffs in delivering services, including hourly wages and benefits that reflect the amounts paid to other workers in each locality. In December 2002, the state filed motions to dismiss the federal and state law claims.

In January 2003, the plaintiffs amended the complaint and asked the court to issue a temporary restraining order to block payment and other funding cuts ordered in August and November 2002 by outgoing Governor Bill Graves to address the state's mounting budget deficit. Included in these cuts were developmental disabilities HCBS waiver rate reductions.

In February 2003, the court turned down the plaintiff's request for a temporary restraining order. The Court ruled that there was no evidence that the state acted "arbitrarily, capriciously or unreasonably in [its] choices of program reductions." While acknowledging that the budget cuts "appear potentially harmful," the "court could not conclude that its interference would not do more harm than good to the public interest if it issued a temporary restraining order." With the rejection of the request for a temporary restraining order, activity in this litigation has returned to the issues raised in the original complaint. The court has heard oral arguments concerning various motions over the past few months.

At a September 2003 hearing, the court observed that it was struggling to understand the issues in the case, including the complexities of the funding of community services in Kansas and whether the plaintiffs had the right to make the claims they had. The court allowed two individuals with developmental disabilities who receive services to be added as plaintiffs. The court decided to allow the lawsuit to go forward, rejecting the state's motion to dismiss except for the claims for retrospective recovery of funds under federal law. In January 2004, the plaintiffs once again asked the court for a temporary restraining order, temporary and permanent injunctions and the appointment of a special master. The court turned down these requests. Over the past several months, the plaintiffs and the state have filed numerous motions, including motions by the state to dismiss plaintiff claims.

#### **10. Louisiana: Malen v. Hood**

This class action complaint was filed in December 2000 against the Louisiana Department of Health and Hospitals in the U.S. District Court for the Eastern District of Louisiana. At issue in this case was the state's proposed method of implementing a new

“Children’s Choices” HCBS waiver program for children with severe disabilities. The new waiver program offers a dollar-capped set of benefits that is less broad than that offered under Louisiana’s pre-existing HCBS waiver program. The state had proposed that, if a child were on the waiting list for Louisiana’s existing HCB waiver program for people with developmental disabilities, the family would have to agree to give up the child’s place on that waiting list if they accepted enrollment in the new waiver program. Families objected to this proviso because it meant that their children would be disadvantaged if they needed more intensive services. Plaintiffs contended that this requirement was impermissible under federal law.

When the lawsuit was filed, federal officials had not yet decided whether to approve the new program. Subsequently, CMS determined that the state’s proposal concerning the waiting-list proviso could not be approved. The state then removed the proviso and CMS approved the waiver request. The Children’s Choices program has since been implemented and the lawsuit has been settled.

#### 11. Maine: *Risinger et al. v. Concannon et al.*

Filed in June 2000, this complaint (00-116-B-C) alleged that Maine violated federal Medicaid law by failing to furnish medically necessary EPSDT services to children with mental disabilities. The lawsuit was filed by private attorneys in collaboration with Maine Equal Justice Partners, Inc. Maine’s Disability Rights Center joined the lawsuit as a named plaintiff. The lawsuit argued that federal law requires the state to arrange for medically necessary EPSDT services – including in-home mental health services – in a reasonably prompt manner. Consequently, at issue was Maine’s assuring access to non-waiver Medicaid services for children. Under federal law, a state may not limit the availability of medically necessary EPSDT services. The lawsuit also contended that Maine’s payments for services were insufficient to ensure their availability when and as needed and thereby the state is violating §1902(a)(30)(A). As a consequence, the plaintiffs argued that 600 Maine children with mental disabilities had been wait listed for services or could not obtain entitled services.<sup>85</sup>

In July 2001, the District Court granted the plaintiff’s motion for class action certification.<sup>86</sup> In May 2002, the parties reached a settlement. Reportedly, the settlement provides that children who need services

will be evaluated more quickly and no child will wait more than six months to receive approved services.

#### 12. Minnesota: *Association for Residential Resources in Minnesota et al. v. Goodno et al. and Masterman et al. v. Goodno*

Both of these lawsuits seek to halt Minnesota’s “rebasings” the amount of funds it allocates to counties for HCBS waiver services for persons with mental retardation and related conditions. In each case, the concern is that rebasing will result in a reduction of funds to individuals. The Association for Residential Resources in Minnesota (ARRM) filed its lawsuit (03-cv-2438) in the U.S. District Court for the District of Minnesota in March 2003. ARRM asked the court to issue a temporary restraining order (TRO) to halt the rebasing until the court could decide the issues in the lawsuit. In March 2003, the court issued the TRO. In April 2003, the court held a hearing concerning the ARRM motion for a preliminary injunction to halt the rebasing and issued the requested TRO. In August, the Court dissolved the TRO and denied an ARRM motion for a new TRO. However, in September 2003, the court agreed to the Masterman plaintiffs’ petition to issue a new TRO. This TRO did not halt the method of rebasing but simply provided that no reduction to the budgets of individual waiver participants could take place because of rebasing until the Court could hear the merits of the ARRM motion for a temporary injunction. With respect to this lawsuit, the parties are in preliminary settlement discussions before the discovery phase begins. The ARRM lawsuit was dismissed in November 2004 after the parties arrived at a settlement agreement.

In April 2003, four individuals and Arc Minnesota filed a similar lawsuit (03cv2939) asking for a preliminary injunction to halt the rebasing. The Minnesota Disability Law Center (the state’s P&A agency) filed this lawsuit on behalf of the plaintiffs. The plaintiffs contend that the payment rebasing will result in “irreparable harm.” It appears that the plaintiffs also argue that rebasing will adversely affect their choice between HCBS waiver and institutional services as well as undermine meeting the essential needs through the waiver program. This lawsuit was transferred to the judge hearing the ARRM lawsuit.

The state filed a motion to dismiss the lawsuit. In its motion to dismiss, the state argued that: (a) the plaintiffs have no right of private action under §1983 to pursue their Medicaid claims under §1902(a)(10)(B) (comparability), §1915(c)(2)(A) (assurance of the health and welfare of HCBS waiver participants), and §1902(a)(1) statewideness of the Social Security Act; (b) plaintiffs lack standing because they cannot show

<sup>85</sup> See also [healthlaw.org/pubs/200006release.html](http://healthlaw.org/pubs/200006release.html).

<sup>86</sup> At [med.uscourts.gov/opinions/carter/2001/GC\\_07022001\\_1-00cv116\\_Risinger\\_v\\_Concannon.pdf](http://med.uscourts.gov/opinions/carter/2001/GC_07022001_1-00cv116_Risinger_v_Concannon.pdf)

that concrete or imminent injury has resulted from rebasing; and, (c) the plaintiffs' ADA claim fails because it attempts to expand the ADA's integration mandate beyond its basic parameters by arguing that the lack of identical funding between institutional and community services is discriminatory.

In October 2003, the Court heard arguments concerning the plaintiffs' request that the court issue a preliminary injunction to halt the rebasing. The state opposed this motion, contending that sufficient funds were now available in the waiver program to ensure that no deep cuts would be made and that the administrative appeals process afforded individuals sufficient protection should their services be reduced.

In January 2004, the court turned down the plaintiffs' motion for a preliminary injunction and dissolved the temporary restraining order against implementation except in the case of the individual plaintiffs.<sup>87</sup> The court decided that it could not continue to block the rebasing, especially because the lawsuit was not a class action. At the same time, however, the court denied the state's motion to dismiss, except for one claim. The court rejected the state's contention that the Gonzaga decision undermined the plaintiffs' standing to bring suit. The Court also rejected the state's request to dismiss the ADA and §504 claims. The Court also expressed the view that the rebasing decision might be at odds with Medicaid statutory provisions concerning the operation of HCBS waiver programs, noting "That Congress has allowed states to limit the number of people served by waivers does not mean that Congress meant to allow states to underserve those actually on the waiver, or treat waiver recipients differently, or excuse states from assuring the health and safety of waiver recipients. Most importantly, it does not evidence that Congress did not intend Medicaid recipients to benefit from the Medicaid program."

In June 2004, the state and the Masterman plaintiffs filed a joint motion asking the court to dismiss this litigation, based on a settlement agreement that they had reached.<sup>88</sup> Under the settlement agreement, the state agreed to increase county allocations over the next two years and issue new guidelines to counties in establishing individual budgets. The state also agreed to contract with an independent consultant to establish a new funding methodology for the waiver program.

<sup>87</sup> The decision is at:

[nysd.uscourts.gov/courtweb/pdf/D08MNXC/04-00195.PDF](http://nysd.uscourts.gov/courtweb/pdf/D08MNXC/04-00195.PDF)

<sup>88</sup> The settlement is described in more detail at:

[arcminnesota.com/Rebasing\\_Settlement.htm](http://arcminnesota.com/Rebasing_Settlement.htm)

### 13. Montana: Sandy L. et al. v. Martz et al.

In September 2002, eight individuals and the Montana Association of Independent Living Services, Inc. (M.A.I.D.S.) filed a class action lawsuit in state court against Governor Judy Martz and the Department of Public Health and Human Services alleging that the state's payments for community services are inadequate and thereby violate the Montana Constitution and other laws concerning the provision of services to individuals with developmental disabilities. The proposed class includes: (a) all persons who receive community services but are at risk of being institutionalized because of the closure, reduction or termination of their services and (b) institutionalized persons who should be served in the community but cannot due to inadequate payments. M.A.I.D.S. is an association of 34 community developmental disabilities provider agencies that furnish HCBS waiver services. The plaintiffs are persons who receive community services. Some persons are served in community residences; others live on their own or with their families.

In the complaint, the plaintiffs argue that state institutional staff is paid between 23 and 38% more than their community counterparts, even though community workers perform much the same work. This wage disparity is alleged to cause high turnover among community workers and providers have a difficult time recruiting workers. As a result of these problems, it is alleged that providers are increasingly unable to meet the needs of many of the individuals they serve, thereby placing individuals at high risk of institutionalization. In addition, the complaint alleges that low payments prevent the placement of institutionalized persons who could be supported in the community.

The plaintiffs argue that the wage disparity between institutional and community workers results in violations of: (a) provisions of Montana law that require the administration of state and federal funds in a fashion that ensures the proper fulfillment of their purpose, including assisting people with developmental disabilities to live as independently as possible and securing "for each developmentally disabled person such treatment and habilitation as will be suited to the needs of the person and assure that such treatment and habilitation are skillfully and humanely administered with full respect for the person's dignity and personal integrity in a community-based setting whenever possible;" (b) provisions of Montana law that set forth the state's policy aims with to people with developmental disabilities, including supporting individuals to live as independently as possible in the least restrictive setting; (c) state statutory provisions that require uniform payment for Medicaid-covered services "where the

actual cost of, quality of, knowledge and skills for the delivery of, and availability of, Medicaid-covered services is equivalent or similar;" and, (d) provisions of the Montana Constitution, including equal protection.

The plaintiffs are seeking preliminary and permanent injunctions to bar the state from maintaining the current disparity in wages and benefits between institutional and community workers. It is estimated that eliminating the disparity in wages and benefits would cost about \$20 million.

#### **14. Ohio: Nikolaus Thompson and Ohio Provider Resource Association et al. v. Hayes et al.**

Filed in June 2003 in the Franklin County Court of Common Pleas, this lawsuit charges that Ohio is violating federal Medicaid law by interfering with the right of individuals to choose their service provider and is not administering Medicaid services for people with developmental disabilities uniformly in all parts of the state.<sup>89</sup> The lawsuit was filed by Ohio's private provider association and individual provider agencies against the Departments of Job and Family Services (Ohio's Medicaid agency) and Mental Retardation and Developmental Disabilities (ODMRDD, which administers the state's HCBS waiver programs for people with developmental disabilities) as well as the superintendents of several county boards of mental retardation and developmental disabilities that administer services locally as well as the Ohio Association of County Boards of Mental Retardation and Developmental Disabilities. At issue in this litigation is the legitimacy of Ohio counties operating Medicaid-funded community services in a fashion that varies county-to-county and, hence, results in disparate treatment of individuals. In 2001, the Ohio legislature directed ODMRDD to promulgate rules to ensure uniform administration of Medicaid services in all counties. To date, such rules have not been adopted and the lawsuit was triggered when private providers faced the prospect of having to sign new contracts with each county by June 30, 2003, even though, in their view such contracts are not legal.

In a press release concerning this lawsuit, the executive director of the provider's association said:

"Federal law is very clear on this point. Medicaid must be administered uniformly across the state. The fact that the State of Ohio has abdicated its responsibility to write uniform administrative rules does not

mean that county boards, which also are substantial service providers in addition to their Medicaid administration roles, can assume powers that are not properly theirs. What we have here is an attempt by county boards and their associations to hijack state law for their own purposes, even though the result will be that individuals with mental retardation and developmental disabilities will not get the same quality of services from county to county."

The plaintiffs asked the court to grant injunctive relief to prevent the county boards from forcing them to sign contracts that they do not regard as legal or withhold payments.

With respect to the injunctive relief, in a June 2003 order<sup>90</sup>, the court directed that county boards and providers should reach mutual agreements to either extend or revise the terms of existing service contracts or otherwise resolve their differences under the state's dispute resolution statute. In the event that the board and providers do not agree, or choose not to enter into a new contract or amend an existing contract, the court instructed both sides to continue to operate under existing contracts, day-to-day until ODMRDD, as the ODJFS designee, promulgates the overdue rules governing service contracts. However, the order also made it clear that a provider's agreeing to continue an existing contract or enter into a new contract with a county board would in no way limit the plaintiffs' pursuing their claims regarding the underlying lawfulness of the contracts.

#### **15. Oklahoma: Fisher et al. v. Oklahoma Health Care Authority et al.**

In 2002, Oklahoma decided that it would limit to five the number of prescribed medications that participants in the state's "Advantage" HCBS waiver program for people with disabilities and older persons could receive in order to reduce spending to address the state's budget deficit. Previously, there was no limit on the number of medications that Advantage participants could receive, a policy that also was in effect for nursing facility residents. Medicaid beneficiaries not served in nursing facilities or participating in the waiver program are subject to a three-prescription limit. Oklahoma's Advantage program covered prescribed drugs over and above this limit as an additional "extended pharmacy" benefit. In limiting prescribed drugs to five per month, the state amended its waiver program to curtail the number of medications provided under the extended pharmacy benefit.

The Oklahoma Disability Law Center immediately filed suit (02-cv-762) in the U.S. District Court for the

<sup>89</sup> For additional information, go to [opra.org/](http://opra.org/) and then look under "What's New" to access documents concerning the lawsuit, including the complaint which is at: [opra.org/pdf/Lawsuit-MemorandumInSupport.PDF](http://opra.org/pdf/Lawsuit-MemorandumInSupport.PDF)

<sup>90</sup> The order is at: [opra.org/pdf/JudgeMcGrathOrder.PDF](http://opra.org/pdf/JudgeMcGrathOrder.PDF)

Northern District of Oklahoma, arguing that limiting the number of medications violated the ADA and §504 because the state continued to allow nursing facility residents an unlimited number of medications. The plaintiffs argued that the state's policy was discriminatory. The district court, however, granted summary judgment to the state, deciding that the plaintiffs could not maintain a claim under the ADA because they were not institutionalized or at risk of institutionalization. The plaintiffs appealed this decision to the 10<sup>th</sup> Circuit Court of Appeals. In July 2003, the Circuit reversed the summary judgment and remanded the complaint to the district court.<sup>91</sup>

The Circuit ruled that the district court had erred in interpreting the ADA and the Olmstead decision as only apply to institutionalized persons or individuals at risk of institutionalization. The Circuit pointed out that Title II applied to all publicly-operated programs that serve people with disabilities. The Circuit also questioned the district court's reasoning that requiring the state to reinstate unlimited prescribed medications would constitute a fundamental alternation. The Circuit noted that, if the effect of the limit were to force individuals to seek care in nursing facilities, the state would incur higher costs because such services are more expensive than waiver services. Since the plaintiffs had not based their original claims on Medicaid law, the Circuit refused to rule on alleged violations of Medicaid requirements that they raised on appeal. These claims revolved around the effect of the waiver of comparability that states receive when they operate an HCBS waiver program and their argument that such a waiver does not extend to other non-waiver Medicaid services. The Circuit noted that these issues would have to be addressed by the district court.

In November 2003, this lawsuit was settled by the parties and dismissed. The Oklahoma Health Care Authority revised its policies concerning prescribed drugs, increasing the prescription limit to six per month for all adult Medicaid beneficiaries. In the case of HCBS waiver participants, in addition to the six prescriptions, they also may have up to seven additional generic prescriptions. Persons who require additional medications may request them through a prior authorization process that will include a clinical review of all the individual's prescribed drugs.

#### **16. Pennsylvania: Network for Quality M.R. Services in Pennsylvania v. Department of Public Welfare**

This lawsuit was filed in March 2002 in the Commonwealth Court of Pennsylvania by a coalition

of agencies that furnish services to individuals in ICFs/MR and/or Pennsylvania's HCBS waiver program for people with mental retardation. The plaintiffs contended that Pennsylvania has depressed payments for ICF/MR services and held down waiver funding by predicating funding levels on inadequate compensation of direct care workers. As a result, the plaintiffs argued that they are cannot furnish an appropriate level of services due to high staff turnover and workforce instability. They also cited a federal review of Pennsylvania's HCBS waiver program that questioned the adequacy of the state's payments for services. The plaintiffs asked the Court to order the state to "fairly, reasonably and lawfully reimburse providers ... to ensure the quality, and continuity, of care provided by these providers."

In particular, the lawsuit contended that the state is in violation of: (a) the State's Public Welfare Code and implementing regulations that require providers to be paid for "reasonable costs"; (b) §1902(a)(30)(A) because payments are insufficient to ensure the quality of care; (c) federal Medicaid requirements by not providing an effective and timely process for the reconsideration of payment rates; and, (d) equal protection under the Pennsylvania Constitution by providing for higher payments to publicly-operated programs than for services furnished by non-state agencies. The plaintiffs asked the Court to order that the state ensure that fair and reasonable direct care staff costs are reimbursed and updated. The plaintiffs also asked for the appointment of a Master to oversee this process. The federal law claims were subsequently dropped by the plaintiffs.

In July 2003, the Commonwealth Court dismissed the lawsuit. The Court found that the plaintiffs had not exhausted their available administrative remedies under Pennsylvania law and, until they had, the issues raised in the lawsuit were not ripe for judicial review.

#### **17. Tennessee: Newberry et al. v. Goetz et al.**

In December 1998, the Tennessee Justice Center (TJC) filed a class action complaint in the U.S. District Court for the Middle District of Tennessee against the state of Tennessee alleging that the state was in violation of federal Medicaid law by impermissibly denying home health benefits to individuals under its TennCare waiver program and, thereby, causing them to be needlessly institutionalized in nursing facilities. Specifically, the complaint claimed violations of federal Medicaid law and the ADA.<sup>92</sup>

<sup>91</sup> Decision located at: [laws.findlaw.com/10th/025192.html](http://laws.findlaw.com/10th/025192.html).

<sup>92</sup> The complaint is at: [injustice.org/TennCare/Newberry/Newberry.html](http://injustice.org/TennCare/Newberry/Newberry.html)

When Tennessee obtained federal approval of its §1115 health care demonstration waiver, it included home health services in the package of benefits that would be furnished by managed care organizations (MCOs) under a capitated payment arrangement. Under the terms of its federally-approved waiver, the state agreed to furnish home health care as “medically necessary” and further agreed not to limit the number of home health visits that a person could receive or restrict the provision of home health services to “homebound” individuals. Nursing facility services were “carved out” of the waiver (i.e., they were excluded from the services that MCOs provide and would continue to be furnished under pre-existing arrangements).

TJC charged that MCOs impermissibly denied home health services in order to hold down their costs and that the state had de facto adopted policies to restrict home health in violation of the terms of the approved waiver. The outcome was the unnecessary institutionalization of individuals who could have remained in the community had they had access to medically necessary home health services. When the lawsuit was filed, the state had set in motion steps to explicitly limit in the waiver the allowable number of home health visits and impose a co-pay requirement as well as eliminate the coverage of private duty nursing. TJC pointed out that the state’s policies led to higher overall expenditures because nursing facility costs were higher than home health costs.

In August 2003, the parties arrived at a settlement agreement. Under the terms of the agreement, the state agreed not to implement its planned restrictions on home health benefits and committed to provide such benefits in accordance with applicable federal regulations (e.g., not condition the provision of home health on a person’s being “homebound” or deny the benefits because they might be required for an extended period of time). In addition, the state agreed to develop HCBS waiver alternatives to nursing facility services.

#### **18. Texas: Frew et al. v. Hawkins et al.**

Filed in 1993, this lawsuit alleged that Texas was not meeting its obligations in furnishing EPDST services to children. In 1996, the state entered into a voluntary consent decree that would be enforceable by the court. The decree required the state to institute detailed procedures to comply with the decree. In 1998, the plaintiffs returned to court, arguing that the state was not living up to the decree. The court agreed and then moved to enforce the decree, prescribing detailed requirements that the state would have to meet. This prompted the state to appeal the district court’s enforcement of the decree to the 5<sup>th</sup> Circuit Court of Ap-

peals. In particular, Texas claimed that it should not be held to the decree because its requirements went well beyond those contained in federal Medicaid law and the decree was not enforceable under the 11<sup>th</sup> Amendment. The 5<sup>th</sup> Circuit ruled in the state’s favor, deciding that the decree could not be enforced unless the state voluntarily waived its 11<sup>th</sup> Amendment immunity.

The plaintiffs then petitioned the U.S. Supreme Court to reverse the 5<sup>th</sup> Circuit’s decision. The plaintiffs contend that the state’s agreeing to the consent decree amounted to a waiver of sovereign immunity and, therefore, the state could not back out of the decree. This litigation raised significant concerns about the enforceability of consent decrees and settlement agreements and thereby their role in resolving litigation.<sup>93</sup> The Supreme Court granted the petition (02-628) and heard oral arguments on October 7, 2003. During the oral arguments, several Justices expressed serious reservations concerning the 5<sup>th</sup> Circuit’s decision.

On January 14, 2004, the Court handed a unanimous decision reversing the 5<sup>th</sup> Circuit decision.<sup>94</sup> Writing for the Court, Justice Kennedy wrote: “Federal courts are not reduced to approving consent decrees and hoping for compliance. Once entered, a consent decree must be enforced.”

#### **Note Concerning Sources**

We scan news articles and other sources for developments concerning the filing of lawsuits in the disabilities arena. We access court websites for updates concerning the status of lawsuits and to obtain primary source documents when they are available on the court’s website. In most cases, federal court documents are only directly available to individuals that have set up a fee-based U.S. PACER system account. To the extent that lawsuits and/or court decisions are posted on websites that are accessible to the general public without charge, we include links in the report. Usually, we do not report on a lawsuit until we have the actual complaint in hand. We also appreciate it when readers of this report alert us that a lawsuit has been filed or when there are new developments in a case.

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<sup>93</sup> For more information, go to: [medill.northwestern.edu/~secure/docket/mt/archives/000721.ph](http://medill.northwestern.edu/~secure/docket/mt/archives/000721.ph)

<sup>94</sup> The decision is at: [laws.findlaw.com/us/000/02-628.html](http://laws.findlaw.com/us/000/02-628.html)

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### **Resources**

The National Health Law Project provides a wealth of information concerning litigation in this arena. This information may be accessed at: [healthlaw.org/](http://healthlaw.org/)

# Address Medicaid's Institutional Bias and Expand Your Practice

PATRICIA E. KEFALAS DUDEK, ESQ.

Aggressive advocacy efforts are happening at the state and national level to address what is called the institutional bias in Medicaid. Essentially, this bias means that, when a person with a disability or an elder is served in an institution or a nursing home, Medicaid will pay for all of his services, including anything related to housing. However, if the same person with a disability or elder lives in a less restrictive set-



ting, and his services are paid for by a Medicaid Waiver, his housing costs are specifically excluded from coverage. See U.S.C. 42 § 1396n(c)(1). The impact of this bias is a huge financial disincentive for the states to move towards true implementation of the Supreme Court's decision in *Olmstead*, 527 U.S. 581 (1999), and the integration mandate of the American with Disabilities Act, 42 U.S.C. § 12101(a)(2) and (5). See also 28 C.F.R. § 35.130(d).

This is how institutional bias works against the states: If a Medicaid beneficiary wants to live in the community, in many cases either the individual or the State will have to pay for the housing costs. If the person pays for this cost, then this is private money

and it cannot be used as state match to draw down additional Medicaid funds. In Michigan, that means a loss of the 50% match of the housing cost (which they get if the person is placed in a more restrictive setting). In some states, the match is even higher. If the State pays for this, these funds need to come from general fund dollars. As the funds are not being used to pay for Medicaid covered services, they again may not be used for Medicaid match. The states are all experiencing a reduction in revenue, with large growth in their Medicaid budget. Therefore, it becomes more difficult for budget directors and policy makers to understand the importance of using these funds to provide long term care services in the community when they can provide these services in a more restrictive setting, and then do not need to come up with as much money to do so.

Advocates for seniors and people with disabilities need to understand this essential policy issue, and need to develop creative strategies to address it and at the same time to achieve the desired goal of many of our clients to age in place, and live in the least restrictive setting. The first strategy to consider is working with Community Non-Profit Housing Corporations.

Non-profits provide a charitable gift to low-income people by arranging for affordable supportive housing; they also lessen the burden of the states by creating and providing safe and affordable supportive community living situations. These charitable organizations capture and preserve the

resources the states spend through the public mental health system and long-term care system on behalf of people with disabilities and seniors. They do this by reinvesting any funds spent, plus the appreciation on the real estate into the development of additional affordable, supportive housing. Without these vital agencies, these often times accessible homes would be in the hands of for profit landlords, and could not be used to defer the continuing obligation of the state to house and provide services to its most vulnerable citizens in the least restrictive setting.

Prior to 1976, Michigan's citizens with developmental disabilities and mental illnesses were typically institutionalized. However, in *Michigan Association for Retarded Citizens v Smith*, 475 F.Supp 990 (ED MI 1979), the State of Michigan agreed to a federal district court judgment requiring the State to provide community based housing for adults with disabilities. The "Plymouth Center" case, as it is now known, was an early part of the national trend toward de-institutionalization, or providing housing and needed services to people with disabilities under the federal Medicaid program in the least restrictive setting. This resulted in the creation of smaller community based residential settings, as opposed to large isolating institutions. Under several administrations, Michigan became a leader in this national effort. In the late 1960s, over 13,000 people with developmental disabilities resided in state-operated institutions across Michigan. Now there are fewer than 100.

Small group homes for six or fewer people proved to be the primary vehicle for complying with the Plymouth consent decree and for implementing a statewide de-institutionalization program. Early on in

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## **Address Medicaid's Institutional Bias, and Expand Your Practice**

(continued from page 12)

this de-institutionalization effort, state and federal funds were used to lease houses from private investors, and services were typically provided under contract with a separate service provider organization. While the housing and support services were separately contracted, they were both provided as a direct responsibility of the State under the Michigan Mental Health Code, §§ 330.1704 and 330.1208, and State Constitution, Article I § 2, and were inextricably linked. Services could not be provided without housing to replace the institution, and housing could not be provided without needed support. The housing and services were so closely tied together that if the person with a disability had a falling out with his service provider, the only choice he had was to move to another setting. This meant that even when a service provider violated the person's rights under the Mental Health Code § 330.1208, or even neglected or abused the person, the person with a disability was punished, as he would have to lose his home and housemates to avoid the provider of services. This model was merely an extension of the institutional model of care, but in smaller settings.

As a result, variations on the group home service delivery model emerged to afford people with disabilities greater protection and choices in housing. Supportive living arrangements are currently offered as a popular alternative to group homes. All of these living arrangements, however, still include some similar type of configuration linking the required elements of housing and support as an alternative to institutional or nursing home care.

In addition to the shift to community based care, Michigan has changed its role from that of a direct provider of services to a director of a state wide system of Community Mental Health boards responsible for providing State Medicaid funded services to eligible low-income citizens with disabilities in its community. The Community Mental Health boards, in essence, act as an agent of the Department of Community Health. They typically contract for the necessary services, although some continue to provide direct services.

Contemporaneous with these systemic changes, a relatively small number of non-profit organizations have emerged to assist the State and the local Community Mental Health boards in providing housing for Medicaid-eligible citizens. These non-profit organizations share a common mission of reducing the burden upon state and local governments in meeting their obligations to citizens under the Medicaid program and the Michigan Mental Health Code.

Nationally, the trend toward de-institutionalization continues. Recent examples include the U.S. Supreme Court *Olmstead* decision, *Olmstead v LC ex rel Zimring*, 527 U.S. 581; 119 S.Ct. 2176; 144 L.Ed.2d 540 (1999), and the President's 2001 "New Freedom" Initiative. The New Freedom Initiative is described by the George W. Bush Administration as one that "promotes the full integration of people with disabilities into all aspects of American life by increasing employment opportunities, by expanding access to technology and public accommodations, and by providing accessible transportation and housing." Without affordable supportive housing options, the objective of delivering services in the "least restrictive setting" cannot be achieved. People with disabilities

and their advocates consider this a basic civil right. Without the efforts of these charities, the burden on the states' Medicaid systems could force people with disabilities and seniors back into institutions and nursing homes.

Many advocates for seniors and people with disabilities throughout the country agree that it is best to have the non-profits focus their efforts on providing housing or social services, but not both. Philosophically, empowering people to be able to select and change service providers without having to lose their homes and friends promotes independence and self-determination. Advocacy groups attested to the validity of this premise; consumers of long term care services can now protect themselves from inadequate care by simply firing the service provider, without fear of losing their home and housemates. This model goes a long way in protecting these citizens and it ensures that the mistakes of Willowbrook and other institutions are not continued (on a much smaller scale) in group homes. See *The End of a Nightmare at Willowbrook*, *Headline News*, Page 2, *Queenscourier*, May 11-17, 2000, for a detailed account of atrocities that took place at the Willowbrook State Institution.

The other rationale for separating the housing and social service functions is for all the organizations to focus on only one of these very important missions, so that they can be even more efficient and effective with the scarce resources allocated to caring for this population. Consistent with this trend, the Department of Housing and Urban Development ("HUD") does not permit tenants to be required to accept services as a condition of living in HUD funded units. See *Federal Register*, Vol. 69, No. 94, May 14

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## Address Medicaid's Institutional Bias, and Expand Your Practice

(continued from page 13)

2004, p.27761. Similarly, the Michigan State Housing Development Authority ("MSHDA") has strongly encouraged the separation of housing from the provision of support services. These non-profit organizations represent the best of the non-profit sector, providing important services that immeasurably benefit people's lives and doing so in an incredibly cost efficient manner, usually on the proverbial shoestring budget.

As a result of working closely with such organizations, I recently found myself drafting Amicus Curiae briefs in their efforts to secure property tax relief for their developments. My advocacy on behalf of individual clients has expanded my practice into areas never anticipated. Forcing these organizations to continue to pay property taxes impedes and restricts their ability to provide this needed charitable resource. If continuously forced to use their limited resources to pay property taxes, they are essentially using one type of tax dollar allocated to house people with disabilities and seniors to pay another type of tax. This is a very inefficient use of these scarce resources and, as a result, people with disabilities and seniors (and those who are responsible for their care) will be forced to divert even more of these scarce resources toward higher housing costs and away from the Medicaid budget, which pays for the services. Ultimately, states will be forced once again to bear more of this financial burden in the future. This burden is even greater as often times these homes are not even allowed the "homestead" valuation, at least under Michigan law, specifically, MCL 211.7cc, for these property taxes.

Another strategy to address the institutional bias is the use of spe-

cial needs trusts to handle the housing costs. It will make it much easier to establish that providing the services in the less restrictive setting is a reasonable accommodation under the ADA if the state does not have to deal with the financial dis-incentive.

Many of the Pooled Accounts Trusts, or Exception C trusts, that I work closely with were developed by nonprofit housing organizations. Many of our sub-accounts hold real estate, and the trust often acts as a "friendly" landlord. Recently, we applied for, and secured a property tax abatement on behalf of the trust by sending the following letter:

*Dear Sir or Madam:*

*Enclosed please find a copy of the Deed showing that the Pooled Account Trust of the Friends of CLS, Inc. f/b/o XXXXXX owns the residence located at XXXX Street, XXX, Michigan XXX. In addition, I have provided copies of the Articles of Organization and the Bylaws for the Friends of CLS, Inc. Friends of CLS, Inc. is a Michigan non-profit corporation granted tax exempt status from the Internal Revenue Service under a ruling dated October 21, 1993. Please note from the enclosed corporate documents that the original name of the organization was the Friends of Wayne County Living Services.*

*The purpose of this correspondence is to request tax exempt status be granted the above-referenced property, under Michigan Compiled Law - MCL 211.7o non-profit charitable institutions; exemptions; definitions. The underlying property should be exempt from Michigan property taxes because one of the charitable purposes of the Friends of CLS, Inc. is to provide housing assistance for individuals who are struggling with a disability. Friends of CLS, Inc. established a Trust to accomplish this charitable*

*purpose. A review of the Trust indicates that the purpose of the Trust is to organize and administer funds in order for individuals with disabilities as defined by Section 614(a)(3) of the Social Security Act, 42 U.S.C. § 1396p, amended August 10, 1993, by the Revenue Reconciliation Act of 1993, to qualify for medically necessary public benefits. The Trust facilitates this purpose by using the assets of the Trust to provide financial assistance to individuals with disabilities, including assistance to defer the cost of supplemental services.*

*Through this Trust, there are many Sub-Trusts wherein each Sub-Trust benefits an individual beneficiary and is designated in the name of such beneficiary. The Trust in question is the Friends of CLS, Inc. Pooled Accounts Trust f/b/o XXXXXXXX. As demonstrated by the enclosed Deed, the Sub-Trust owns the residence now being used as XXXXXXXXh's semi-independent living arrangement.*

*To qualify for the exemption, the property owner must satisfy the following requirements:*

*The real estate must be owned and occupied by the exemption claimant;*

*The exemption claimant must be a library, charitable, educational or scientific institution;*

*The claimant must have been incorporated under the laws of the State of Michigan;*

*The exemption exists only when the building or other property therein, are occupied by the claimant solely for the purposes for which it was incorporated.*

*From the above standard, the Trust should be granted the exemption.*

*The Trust is currently owned and occupied by the Friends of CLS, Inc. Pooled Accounts Trust f/b/o XXXXXXXX. By the terms of the Pooled Accounts Trust, Sub-Trust and the main Trust, the Trust can only benefit an individual who is cop-*

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## Address Medicaid's Institutional Bias, and Expand Your Practice

(continued from page 14)

ing with a disability. Assisting individuals with a disability falls directly within the charitable purposes Section 501(c)(3). When XXXXX passes away, the Terms of Trust require the property to be used for supportive housing for people with disabilities who are indigent under Section XI (2).

The enclosed Articles of Incorporation show that Friends of CLS, Inc. is in fact incorporated in the State of Michigan and is a non-profit entity. The Friends of CLS, Inc. chose to utilize the Trust to accomplish this goal of providing and assisting individuals with disabilities.

The purposes for which all of the above-referenced entities were established is the charitable purpose of supporting individuals with disabilities. Providing support for the housing needs for XXXXXX, an individual with disabilities, fulfills the Friends of CLS, Inc. charitable purpose and thus satisfies this requirement for a property tax exemption.

We request that you modify your tax records to indicate that the above-referenced parcel is exempt from taxation until it is transferred or is no longer engaged in this charitable purpose.

It is important that NAELA members understand the system barriers that make it difficult for us to assist our clients that desire to live in places other than nursing homes and institutions. I encourage you to use your advocacy skills to address the Medicaid institutional bias, and, who knows, you just might end up expanding your practice into new areas at the same time.

Patricia E. K. Dudek, Esq., practices Elder Law in Bloomfield Hills, MI.

## Memoirs of a Counsellor: "After So Much Time..."

BRIDGET O'BRIEN SWARTZ, ESQ.  
(AKA SOCIAL WORKER AT HEART)

Ah, Maggie. After nearly eight years serving as your counsellor, advocate, I've finally become a part of the conspiracy against you. It was inevitable, I suppose.

I was "forced" to be your attorney by order of the court, after you expressed dissatisfaction with your former court-appointed attorney. I, and others, often wondered why I did more than what is normally required of a court-appointed attorney. Those of us who practice law, particularly, those of us who are Elder Law attorneys, all have at least one, probably more such cases for which the reason we feel a strong connection is uncertain.

Yes, you were a challenge, lacking insight into your mental illness, blaming others for your circumstances, impossible to reason with... But that's the nature of your illness, isn't it? I often wondered why those with training and experience in dealing with persons such as yourself were repeatedly at a loss as to how to "treat" you. Talking around you, as if you weren't present. Talking condescendingly, despite acknowledgement of your intelligence.

The least I could do was be present, unlike your family, and stand at your side when you so often believed the world was against you. Sometimes I believed that as well! You trusted me and I gave you hope. Why? I do not know. Maybe it was because I would see and believe what was truth when no one else could sift through the delusions or rise above their frustrations.

And now, even I cannot help or give you encouragement as, in your eyes, I'm "one of them." So, it's the end of an era, so to speak. I hope your new "counsellor" is able to do for you what I no longer can. But in my heart of hearts, I unfortunately know that the next person won't have the same will or desire; won't recognize that you have no one else who'll accept you for who you are. What was a case that stood out from the rest for me, will just be one of many for the next person. Ah, Maggie . . .



Bridget O'Brien Swartz, Esq., practices Elder Law in Phoenix, AZ.

## Sample Cover Letter

[Date]

[Address]

**Re: Request for Community Based Services under State's Waiver Program**

Dear Medicaid Consumer:

[Name of Senior or Individual with a disability] recently requested participation in the State's waiver program (the "Program") for community based services, i.e., Alternative Services. I also understand that \_\_\_\_\_ [Name of Senior or Individual with a disability] was denied participation in the Program and/or was placed on a "waiting list," as the waiver slots are currently full.

Please be aware that \_\_\_\_\_ [Name of Senior or Individual with a disability]'s civil rights may be violated by the State and its agencies under the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, the State's applicable civil rights acts, and certain other federal and State laws and regulations relating to Medicaid programs/activities. It is unlawful for anyone to discriminate based upon an individual's disability and force you to accept a nursing home as your only choice for your significant long term care needs. However, there is recourse that may be taken to draw attention to the issue.

Attached are the following:

1. Frequently Asked Questions and Answers regarding how to respond to a potential civil rights issue and Instructions on how to file a complaint.
2. A sample Complaint form. You can use this sample to fill out a similar complaint on your own behalf. The process is free and can be done by email, fax, or mail, a blank form is also attached.
3. A sample pleading, which can be modified and used to file suit on your behalf.

As an advocate for seniors or individuals with disabilities who need long term care, I encourage your efforts to secure services in the least restrictive setting. Good luck!

Very truly yours,

Enclosure

*victor/misc/ada complaint-sample ltr*



DEPARTMENT OF HEALTH AND HUMAN SERVICES  
OFFICE FOR CIVIL RIGHTS (OCR)  
**DISCRIMINATION COMPLAINT**

Form Approved: OMB No. 0990-0269.  
See OMB Statement on Reverse.



If you have questions about this form, call OCR (toll-free) at:  
1-800-368-1019 (any language) or 1-800-537-7697 (TDD)

YOUR FIRST NAME Brian		YOUR LAST NAME Smith	
HOME PHONE ( 749 ) 222-3333		WORK PHONE (749) 111-2222	
STREET ADDRESS 200 Parkway			CITY Somewhere
STATE Michigan	ZIP 48304	E-MAIL ADDRESS (if available)	

Are you filing this complaint for someone else?  Yes  No

If Yes, against whom do you believe the discrimination was directed?

FIRST NAME Michelle	LAST NAME Yates
------------------------	--------------------

I believe that I have been (or someone else has been) discriminated against on the basis of: *\*please note you can mark both age & disability*

- Race / Color / National Origin     Age     Religion     Gender (Male/Female)  
 Disability     Other (specify): \_\_\_\_\_

Who do you think discriminated against you (or someone else)?

PERSON/AGENCY/ORGANIZATION  
Waiver Agency and Michigan Department of Community Health

STREET ADDRESS 6 <sup>th</sup> Floor Louis Cass Bldg., 320 S. Walnut		CITY Lansing
STATE Michigan	ZIP 48913	PHONE (517) 373-3500

When do you believe that the discrimination took place?

LIST DATE(S)  
May 13, 2004 to Present

Describe briefly what happened. How and why do you believe you (or someone else) were discriminated against? Please be as specific as possible. (Attach additional pages as needed)

I am an attorney filing this complaint on behalf of Michelle Yates. Michelle applied for the home/community services pursuant to the federally funded Medicaid waiver program administered by Michigan Department of Community Health [state organization]. Michelle was denied the alternative services in violation of the ADA and its implementing regulations, and Section 504 of the Rehabilitation Act and its implementing regulations (28 C.F.R. 41.51; 45 C.F.R. 84.4), Townsend v. Quasim [328 F3d 511 (9<sup>th</sup> Cir. 2003)] and Olmstead v. Zimring (527 U.S. 581, 119 S.Ct. 2176).

Please sign and date this complaint.

SIGNATURE	DATE
-----------	------

Filing a complaint with OCR is voluntary. However, without the information requested above, OCR may be unable to proceed with your complaint. We collect this information under authority of Title VI of the Civil Rights Act of 1964, Section 504 of the Rehabilitation Act of 1973 and other civil rights statutes. We will use the information you provide to determine if we have jurisdiction and, if so, how we will process your complaint. Information submitted on this form is treated confidentially and is protected under the provisions of the Privacy Act of 1974. Names or other identifying information about individuals are disclosed when it is necessary for investigation of possible discrimination, for internal systems operations, or for routine uses, which include disclosure of information outside the Department for purposes associated with civil rights compliance and as permitted by law. It is illegal for a recipient of Federal financial assistance from Health and Human Services (HHS) to intimidate, threaten, coerce, or discriminate or retaliate against you for filing this complaint or for taking any other action to enforce your rights under Federal civil rights laws. You are not required to use this form. You also may write a letter or submit a complaint electronically with the same information. To submit an electronic complaint, go to our web site at: [www.hhs.gov/ocr/discrimhowtofile.html](http://www.hhs.gov/ocr/discrimhowtofile.html). To mail a complaint see reverse page for OCR Regional addresses.

(The remaining information on this form is optional. Failure to answer these voluntary questions will not affect OCR's decision to process your complaint.)

Do you need special accommodations for us to communicate with you about this complaint (check all that apply)?

- Braille       Large Print       Cassette tape       Computer diskette       Electronic mail       TDD
- Sign language interpreter (specify language): \_\_\_\_\_
- Foreign language interpreter (specify language): \_\_\_\_\_       Other: \_\_\_\_\_

If we cannot reach you directly, is there someone we can contact to help us reach you?

FIRST NAME		LAST NAME	
HOME PHONE (    )		WORK PHONE (    )	
STREET ADDRESS		CITY	
STATE	ZIP	E-MAIL ADDRESS (If available)	

Have you filed your complaint anywhere else? If so, please provide the following. (Attach additional pages as needed.)

PERSON / AGENCY / ORGANIZATION / COURT NAME(S)

DATE(S) FILED On or about July 22, 2004	CASE NUMBER(S) (If known)
--	---------------------------

To help us better serve the public, please provide the following information for the person you believe was discriminated against (you or the person on whose behalf you are filing).

ETHNICITY (select one)      RACE (select one or more)

Hispanic or Latino       American Indian or Alaska Native       Asian       Native Hawaiian or Other Pacific Islander

Not Hispanic or Latino       Black or African American       White       Other (specify): \_\_\_\_\_

PRIMARY LANGUAGE SPOKEN (if other than English)	HOW DID YOU LEARN ABOUT THE OFFICE FOR CIVIL RIGHTS?
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To mail a complaint, please type or print, and return completed complaint to the OCR Regional Address based on the region where the alleged discrimination took place.

<b>Region I - CT, ME, MA, NH, RI, VT</b> Office for Civil Rights Department of Health & Human Services JFK Federal Building - Room 1875 Boston, MA 02203 (617) 565-1340; (617) 565-1343 (TDD) (617) 565-3809 FAX	<b>Region V - IL, IN, MI, MN, OH, WI</b> Office for Civil Rights Department of Health & Human Services 233 N. Michigan Ave - Suite 240 Chicago, IL 60601 (312) 886-2359; (312) 353-5693 (TDD) (312) 886-1807 FAX	<b>Region IX - AZ, CA, HI, NV, AS, GU,</b> The U.S. Affiliated Pacific Island Jurisdictions Office for Civil Rights Department of Health & Human Services 50 United Nations Plaza - Room 322 San Francisco, CA 94102 (415) 437-8310; (415) 437-8311 (TDD) (415) 437-8329 FAX
<b>Region II - NJ, NY, PR, VI</b> Office for Civil Rights Department of Health & Human Services 26 Federal Plaza - Suite 3313 New York, NY 10278 (212) 264-3313; (212) 264-2355 (TDD) (212) 264-3039 FAX	<b>Region VI - AR, LA, NM, OK, TX</b> Office for Civil Rights Department of Health & Human Services 1301 Young Street - Suite 1169 Dallas, TX 75202 (214) 767-4056; (214) 767-8940 (TDD) (214) 767-0432 FAX	
<b>Region III - DE, DC, MD, PA, VA, WV</b> Office for Civil Rights Department of Health & Human Services 150 S. Independence Mall West - Suite 372 Philadelphia, PA 19106-3499 (215) 861-4441; (215) 861-4440 (TDD) (215) 861-4431 FAX	<b>Region VII - IA, KS, MO, NE</b> Office for Civil Rights Department of Health & Human Services 601 East 12th Street - Room 248 Kansas City, MO 64106 (816) 426-7278; (816) 426-7065 (TDD) (816) 426-3686 FAX	<b>Region X - AK, ID, OR, WA</b> Office for Civil Rights Department of Health & Human Services 2201 Sixth Avenue - Mail Stop RX-11 Seattle, WA 98121 (206) 615-2290; (206) 615-2296 (TDD) (206) 615-2297 FAX
<b>Region IV - AL, FL, GA, KY, MS, NC, SC, TN</b> Office for Civil Rights Department of Health & Human Services 61 Forsyth Street, SW. - Suite 3B70 Atlanta, GA 30323 (404) 562-7886; (404) 331-2867 (TDD) (404) 562-7881 FAX	<b>Region VIII - CO, MT, ND, SD, UT, WY</b> Office for Civil Rights Department of Health & Human Services 1961 Stout Street - Room 1426 Denver, CO 80294 (303) 844-2024; (303) 844-3439 (TDD) (303) 844-2025 FAX	

**Burden Statement**

Public reporting burden for the collection of information on this complaint form is estimated to average 45 minutes per response, including the time for reviewing instructions, gathering the data needed and entering and reviewing the information on the completed complaint form. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a valid control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: HHS/OS Reports Clearance Officer, Office of Information Resources Management, 200 Independence Ave., S.W., Room 531H, Washington, D.C. 20201.



# FACT SHEET



U.S. Department of Health and Human Services • Office for Civil Rights

## HOW TO FILE A DISCRIMINATION COMPLAINT WITH THE OFFICE FOR CIVIL RIGHTS

The Department of Health and Human Services (HHS) Office for Civil Rights (OCR) enforces certain Federal civil rights laws that protect the rights of all persons in the United States to receive health and human services without discrimination based on race, color, national origin, disability, age, and in some cases, sex and religion.

If you believe that you have been discriminated against because of your race, color, national origin, disability, age, sex or religion by a health care or human services provider (such as a hospital, nursing home, social service agency, etc.) or by a State or local government health or human services agency, you may file a complaint with the Office for Civil Rights (OCR). Complaints alleging discrimination based on disability by programs directly operated by HHS may also be filed with OCR. You may file a complaint for yourself or for someone else.

Complaints to the Office for Civil Rights should be filed in writing, either on paper or electronically. You can use OCR's [Discrimination Complaint Form](#) which can be found on our web site or at an OCR Regional office. If you do not use OCR's form, your complaint should include the following information:

1. Your name, address and telephone number.
2. If you are filing a complaint for someone else, include that person's name, address and telephone number.
3. The name and address of the organization or person you believe discriminated against you.
4. How, why and when you believe you (or the person on whose behalf you are filing the complaint) were discriminated against.
5. Any other information that would help OCR understand your complaint.

You must file your complaint within 180 days of the date when the discrimination happened. OCR may extend the 180-day period if you can show "good cause."

You can file your complaint by email at [OCRcomplaint@hhs.gov](mailto:OCRcomplaint@hhs.gov), or you can mail or fax your complaint to the OCR Regional Office that is responsible for the state in which you allege the discrimination took place. To find out where to file your complaint, use the [OCR Regions list](#) at the end of this Fact Sheet or you can look at the [regional office map](#) to help you determine where to send your complaint.

### MORE INFORMATION ABOUT HOW TO GET A COPY OF OCR'S DISCRIMINATION COMPLAINT FORM

*Option 1:* Open and print out the [Discrimination Complaint Form](#) in PDF format (you will need Adobe Reader software) and fill it out. Return the completed complaint to the appropriate OCR Regional Office by mail or fax.

*Option 2:* Download the [Discrimination Complaint Form](#) in Microsoft Word format to your own computer, fill out and save the form using Microsoft Word. Use the Tab and Shift/Tab on your keyboard to move from field to field in the form. Then, you can either: (a) print the completed form and mail or fax it to the appropriate OCR Regional Office; or (b) email the form to OCR at [OCRComplaint@hhs.gov](mailto:OCRComplaint@hhs.gov).

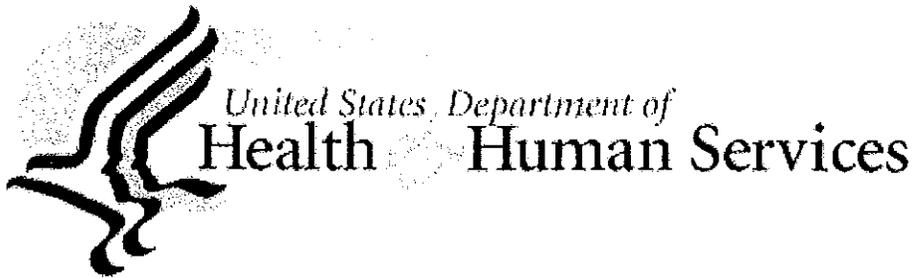
If you have any questions, or need help to file your complaint, call OCR (toll-free) at 1-800-368-1019 (voice) or 1-800-537-7697 (TDD). You may also send an email to [OCRMail@hhs.gov](mailto:OCRMail@hhs.gov).

Website: <http://www.hhs.gov/ocr>

<b>OCR Regional Addresses</b>	
<p><b>Region I - CT, ME, MA, NH, RI, VT</b> Office for Civil Rights U.S. Department of Health &amp; Human Services JFK Federal Building - Room 1875 Boston, MA 02203 (617) 565-1340; (617) 565-1343 (TDD) (617) 565-3809 FAX</p>	<p><b>Region VI - AR, LA, NM, OK, TX</b> Office for Civil Rights U.S. Department of Health &amp; Human Services 1301 Young Street - Suite 1169 Dallas, TX 75202 (214) 767-4056; (214) 767-8940 (TDD) (214) 767-0432 FAX</p>
<p><b>Region II - NJ, NY, PR, VI</b> Office for Civil Rights U.S. Department of Health &amp; Human Services 26 Federal Plaza - Suite 3313 New York, NY 10278 (212) 264-3313; (212) 264-2355 (TDD) (212) 264-3039 FAX</p>	<p><b>Region VII - IA, KS, MO, NE</b> Office for Civil Rights U.S. Department of Health &amp; Human Services 601 East 12<sup>th</sup> Street - Room 248 Kansas City, MO 64106 (816) 426-7278; (816) 426-7065 (TDD) (816) 426-3686 FAX</p>
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<p><b>Region V - IL, IN, MI, MN, OH, WI</b> Office for Civil Rights U.S. Department of Health &amp; Human Services 233 N. Michigan Ave. - Suite 240</p>	<p><b>Region X - AK, ID, OR, WA</b> Office for Civil Rights U.S. Department of Health &amp; Human Services 2201 Sixth Avenue - Mail Stop RX-11 Seattle, WA 98121</p>

Chicago, IL 60601  
(312) 886-2359; (312) 353-5693 (TDD)  
(312) 886-1807 FAX

(206) 615-2290; (206) 615-2296 (TDD)  
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## Office for Civil Rights

### Frequently Asked Questions with Answers

- **Q. What are civil rights?**
- A. Civil rights are personal rights guaranteed and protected by the U.S. Constitution and by subsequent acts of Congress, such as the Civil Rights Act of 1964. They include, for example, the right to free speech, due process, equal protection of the laws and to be free from discrimination. Our office enforces part of certain statutorily-created civil rights. As far as HHS goes, all persons in the United States have a right to receive services in a nondiscriminatory manner from state and local social and health services agencies, hospitals, clinics, nursing homes or other agencies receiving funds from HHS. For example, you cannot be denied services or benefits, simply because of your race, national origin, or disability.
- **Q. How does one file a complaint at the Office for Civil Rights?**
- A. If you believe discrimination has happened to you or any specific class of individuals because of race, color, national origin, age, sex, disability or religion by a health care or human services provider (such as hospitals, nursing homes, social service agencies, etc.), you or your representative may file a complaint with the Office for Civil Rights (OCR). Complaints against the U.S. Department of Health and Human Services alleging discrimination in services on the basis of disability may also be filed with OCR.
- **Q. Is there a timeframe for filing a complaint with the Office for Civil Rights?**
- A. Complaints usually must be filed within 180 days from the date of the alleged discriminatory act. (OCR may extend the 180-day period if good cause to do so is shown.)
- **Q. What information is needed for one to file a complaint?**
- A. Include the following information in your written complaint ( request a Discrimination Complaint Form from OCR or at <http://www.hhs.gov/ocr/disform.html>. You will need to save the form to a disk):
  - Your name, address and telephone number. You must sign the complaint. (If you file a complaint on someone's behalf, include his/her name, address and telephone number and state your relationship to that person - e.g., spouse, attorney, friend, etc.)
  - Name and address of the institution or agency you believed discriminated against you.
  - How, why and when you believe you were discriminated against. - Any other relevant information.
- **Q. What happens with my complaint once the Office for Civil Rights receives it.**
- A. Determining Jurisdiction - Once a complaint is received, OCR must determine if it has the legal authority to review and investigate the complaint. Our authority primarily is over those entities (known as "Recipients") receiving federal financial assistance from the Department of Health and Human Services (DHHS) and in certain cases over entities for which OCR has been designated enforcement responsibility by another agency.

- **Q. How does your office respond to my concern for privacy and confidentiality.**
- A. Privacy Act Notice/Confidentiality - In OCR investigations, the name of the complainant usually is kept confidential unless its' disclosure is necessary to the case. If OCR determines that release of your identity is required for the processing of the case, you will be asked to sign a release. If you choose not to provide a release, the investigation may be impeded or terminated.
  
- **Q. How does the Office for Civil Rights conduct an investigation of my complaint?**
- A. Once it is clear that OCR has jurisdiction to handle your complaint, the investigator will gather information through interviewing witnesses, obtaining documentation, and making visits to appropriate sites. You may be interviewed again as information is gathered.
  
- **Q. What kind of notification do I receive, when the Office for Civil Rights has completed an investigation?**
- A. At the conclusion of an investigation, OCR issues a Letter of Findings, which presents OCR's decision on whether there has been a violation of a federal statute or regulation. If there is a violation finding, the recipient is then allowed a specific time period, usually 60 days, to correct the violation or provide OCR with a plan of correction. Corrective action may involve a change in policy or procedure, provision of a service, reinstatement to a job, backpay, restoration of lost benefits, or a notice to clients and employees that a recipient has taken steps to comply with with a federal statute or regulation. If a recipient is unwilling to take corrective action to come into compliance, OCR will recommend that enforcement proceedings be initiated. A final decision upholding a finding of a violation may result in the termination of Federal financial assistance to the recipient.
  
- **Q. Am I able to initiate a private court action?**
- A. Under most of the statutes enforced by OCR, a complainant who has been discriminated against may initiate private court action instead of, or in addition to filing a complaint with OCR. If you are interested in doing so, you should consult an attorney as soon as possible to ensure that the action will be timely filed.
  
- **Q. If I believe that I have been denied health or human services or treated in an unfair manner because of my race, color, national origin, disability or age, where do I go and what do I do?**
- A. Contact the OCR regional office that serves your state. Describe your situation in writing to the OCR regional staff and they will advise you and if necessary assist you in filing a civil rights complaint with the office. They will then investigate the complaint and issue a Letter of Findings to you and the alleged discriminating party. If the alleged discriminating health or human service agency has violated your civil rights, the Office for Civil Rights will seek an appropriate remedy in an attempt to rectify the discrimination.
  
- **Q. What is the extent of your geographical coverage?**
- A. If a complainant alleges discrimination by a DHHS funded health or human services entity in:
  1. Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island, and/or Vermont, the Boston Regional Office will handle the complaint. If the entity is outside of these states, the office will forward the complaint to the appropriate OCR regional office.
  2. New Jersey, New York, Puerto Rico and/or the Virgin Islands, the New York Regional Office will handle the complaint. If the entity is outside of these states, the office will forward the complaint to the appropriate OCR regional office.
  3. Delaware, the District of Columbia, Maryland, Pennsylvania, Virginia, and/or West Virginia, the Philadelphia Regional Office will handle the complaint. If the entity is outside of these states, the office will forward the complaint to the appropriate OCR regional office.
  4. Alabama, Florida, Georgia, Kentucky, Mississippi, North and South Carolina, and/or Tennessee, the Atlanta Regional Office will handle the complaint. If the entity is outside of these states, the office will forward the complaint to the appropriate OCR regional office.
  5. Illinois, Indiana, Michigan, Minnesota, Ohio, and/or Wisconsin, the Chicago Regional Office will handle the complaint. If the entity is outside of these states, the office will forward the complaint to the appropriate OCR regional office.
  6. Arkansas, Louisiana, New Mexico, Oklahoma, and/or Texas, the Dallas Regional Office will handle the complaint. If the entity is outside of these states, the office will forward the complaint to the appropriate OCR

regional office.

7. Iowa, Kansas, Missouri, and/or Nebraska, the Kansas City Regional Office will handle the complaint. If the entity is outside of these states, the office will forward the complaint to the appropriate OCR regional office.
8. Colorado, Montana, North and/or South Dakota, Utah, and/or Wyoming, the Denver Regional Office will handle the complaint. If the entity is outside of these states, the office will forward the complaint to the appropriate OCR regional office.
9. Arizona, California, Hawaii, Nevada, Guam, Pacific Islands, and/or American Samoa, the San Francisco Regional Office will handle the complaint. If the entity is outside of these states, the office will forward the complaint to the appropriate OCR regional office.
10. Alaska, Idaho, Oregon, Washington, the Seattle Regional Office will handle the complaint. If the entity is outside of these states, the office will forward the complaint to the appropriate OCR regional office.

• **Q. What happens if the Office for Civil Rights cannot help me?**

- A. The Office for Civil Rights will try to identify the appropriate state or federal agency and refer your case unless you tell us not to.

• **Q. Are there other federal agencies that protect my rights?**

- A. Other Federal and State agencies exist to protect your rights. Some are:  
 Education - Office for Civil Rights, U.S. Department of Education  
 Employment - Equal Employment Opportunity Commission (EEOC); Office of Federal Contract Compliance Programs, U.S. Department of Labor  
 Housing - Office of Fair Housing, U.S. Department of Housing and Urban Development. More than one agency may be able to help you.

• **Q. I've talked to one of your representatives about a problem with the police harassing my son because he is African American and was told that your office cannot take the case. Why can't your office do something? His civil rights are being violated!**

- A. This office is a civil rights office within the U.S. Department of Health and Human Services. As such, our jurisdiction is generally limited to complaints of discrimination filed against providers of health and social services who receive Federal financial assistance from our Department. The Department of Justice (DOJ) usually handles complaints against law enforcement agencies. You may wish to call DOJ at 1-800-869-4499.

• **Q. What is Federal financial assistance?**

- A. Examples of Federal financial assistance as defined by our regulations include Medicaid, Medicare Hospital Insurance (Part A), Public Health Service grants, Aid to Families with Dependent Children. These funds are given to a facility (such as a hospital, social service agency) or an individual service provider (such as a doctor, dentist) by the government for services provided or to provide a service. Social security benefits, Supplemental Security Income, Medicare Supplemental Medical Insurance (Part B) are not considered Federal financial assistance when applying the civil rights laws OCR enforces. Generally speaking, the reason for this is that these sources of funding are paid directly to an individual beneficiary by the government.

• **Q. I inquired about filing a complaint against a major university and was told that I should file with the Department of Education's Office for Civil Rights. I was not given a reason for this referral. I know that the university receives millions from your agency, so why can't your agency accept the complaint?**

- A. It is possible for several Departments to have provided Federal financial assistance to that University. In order to avoid duplication of effort and to be more efficient, we coordinate our activities with other agencies to determine which agency would be the most appropriate agency to handle your complaint. This decision is made on a case by case basis with many factors considered. Some of these factors include, the subject matter, which department provides the largest portion of Federal financial assistance, whether an agency has started an investigation. Generally, DHHS does not investigate educational institutions unless the complaint is against a health related portion of the University, e.g., the University's School of Medicine.

• **Q. Do I have to be a minority person in order to have "civil rights"?**

- A. All persons in the United States have civil rights under the constitution and appropriate laws. DHHS is charged with enforcing only a few of these civil rights laws. For example, Title VI of the Civil Rights Act of 1964 prohibits discrimination on the ground of race, color, and national origin. A common misperception is that this law is for the exclusive use of "minorities." This law does not exclude non-minority persons. In other words, this law provides protection to all persons living in the United States from discrimination on the basis of race, color, or national origin. In addition, we enforce other laws that protect persons from discrimination on the bases of disability, sex, age, etc. A person of any race can have a disability, and sex and age are not exclusive characteristics of a minority person. As such, laws prohibiting discrimination protect ALL persons.
- **Q. Does OCR have the authority to investigate discrimination complaints filed against programs that provide low income persons with free or reduced cost health care?**
- A. Yes, we have the authority to investigate such complaints if the following conditions are met:
  - \* the facility receives Federal financial assistance from DHHS - in addition, if the alleged discrimination involves disability, we can accept complaints filed against a State or local government entity providing health or social services even if it does not receive Federal financial assistance, and we can accept complaints of disability discrimination in programs conducted by DHHS.
  - \* the alleged discrimination must be on a basis in which we have authority (e.g., race, disability) the subject matter must be covered by our regulations (e.g., we generally do not accept employment complaints based on race; the Equal Employment Opportunity Commission usually handles such complaints.)
  - \* the complaint must be filed within 180 days of the alleged discrimination, unless a waiver is granted
  - \* the complaint must be in writing and signed
- **Q. I have a young child who is occasionally quite sick because he has AIDS. I've tried to enroll him in a day-care center near my house, but was told that they do not take children who have AIDS because of the danger that it would pose to other children. What can I do?**
- A. It is unlawful for a public or private facility to discriminate against a person based solely on his/her disability if that person is a qualified person with a disability and meets the eligibility criteria to receive benefits or services. Each complaint, however, is examined on a case by case basis. Specifically, in cases involving AIDS, an issue that may come up is whether the person poses a significant threat to the health and safety of others. Generally speaking, in a day care setting, having AIDS itself should not disqualify a child from participation. You may contact our office to speak to one of our investigators.
- **Q. I'm a disabled person. I called your office to file a complaint and was told that your office cannot help me. What do I have to do to have a complaint accepted for investigation by your office?**
- A. In order for our office to accept a complaint for investigation, the following conditions must be met:
  - \* You must identify the alleged discriminating entity or agency, you must identify the alleged injured party (the person who was allegedly discriminated against), the alleged discrimination must be on a basis in which we have jurisdiction (e.g., race, disability).
  - \* OCR must have authority to investigate the facility you are complaining against. The facility must receive funds from DHHS, OR if the alleged discrimination is on the basis of disability the facility can also be a DHHS conducted program, or a state or local government entity providing health or social services.
  - \* The subject matter must be covered by our regulations. For example, we generally do not accept employment complaints based on race because the Equal Employment Opportunity Commission usually handles such complaints. The complainant must clearly state why the action taken was based on the complainant's protected basis. For example, having a disability, by itself, does not protect a person from having an adverse action taken against him. It is unlawful only if the adverse action is taken because of the person's disability. A hearing impaired person cannot be denied services solely because a hospital does not want to provide a sign language interpreter. However, a hearing impaired person may be legitimately refused additional non-emergency services by a hospital for failing to pay his bills.
  - \* The complaint must be filed within 180 days of the alleged discrimination, unless a waiver is granted.
  - \* The complaint must be in writing and signed.
- **Q. I called your office regarding being fired from my job at a local supermarket because of age**

**discrimination and your office said that it could not accept my complaint. Whom should I call for assistance?**

- A. Generally speaking, most employment discrimination complaints, especially those against private employers, should be addressed to the local Equal Employment Opportunity Commission that services the state in which you reside.
  
- **Q. My constitutional, human and civil rights have been violated. Why can't your office help me?**
- A. OCR's charge is to ensure that the civil rights laws under our jurisdiction are not violated. OCR enforces laws prohibiting discrimination on the bases of disability, age, race, color, national origin, sex and religion in the provision of health and social services. OCR can investigate only those matters that are covered by the laws it enforces.
  
- **Q. Can your office represent me in my complaint?**
- A. No. OCR is a neutral fact finding agency. Our charge is to ensure that the laws under our jurisdiction are not violated. If your complaint is accepted for investigation, we may, for example, obtain a promise that the program will change its practices or provide you with a service. Although we will consult with you, you may not be satisfied with any individual remedies proposed. You should consult an attorney about your right to file a private law suit in court if you wish to protect fully your individual rights and remedies. Delay in doing so may foreclose your right to bring a law suit.
  
- **Q. If you can't represent me, do you think the ACLU will help?**
- A. The ACLU is not a government agency, and it decides what issues to become involved in on a case by case basis. The concept of civil liberties encompasses many more issues than discrimination prohibited by the laws enforced by OCR. It also concerns individual freedom issues found in the Constitution -- freedom of speech, association, religion are counted in the civil liberties category. For further information, call the local ACLU office in your area.

Last revised: December 12, 2003

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U.S. Department of Health & Human Services • 200 Independence Avenue, S.W. • Washington, D.C. 20201

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**UNITED STATES DISTRICT COURT  
IN THE \_\_\_\_\_ DISTRICT OF MICHIGAN  
\_\_\_\_\_ DIVISION**

\_\_\_\_\_

Plaintiff,

vs.

\_\_\_\_\_

**[Defendant/Defendants].**

\_\_\_\_\_/

**[Name of Attorney(s)]**

Attorney(s) for Plaintiff

**[Address and phone number]**

\_\_\_\_\_ /

**COMPLAINT AND JURY DEMAND**

There is no other civil action between these parties arising out of the same transaction or occurrence as alleged in this Complaint pending in this Court, nor has any such action been previously filed and dismissed or transferred after having been assigned to a Judge.

NOW COMES Plaintiff \_\_\_\_\_, by and through **[his/her]** attorney, \_\_\_\_\_ **[attorney/firm name]** and for **[his/her]** Complaint against **[Defendant/Defendants]** \_\_\_\_\_ hereby states as follows:

**JURISDICTION AND VENUE**

1. Plaintiff brings this action under the Americans with Disabilities Act, 42 U.S.C. §12101, *et seq.* (“ADA”), Section 504 of the Rehabilitation Act of 1973, as amended,

at 29 U.S.C. §794 (the “Rehabilitation Act”), and the Persons With Disabilities Civil Rights Act, M.C.L. §37.1101, *et seq.* (“PDCRA”).

2. This Court has jurisdiction pursuant to the following statutes:

a. 28 U.S.C. §1331, which gives district courts original jurisdiction over civil actions arising under the Constitution, laws or treaties of the United States;

b. 28 U.S.C. §1343 (3) and (4), which gives district courts jurisdiction over actions to secure civil rights extended by the United States government;

c. 28 U.S.C. §1367, which gives the district court supplemental jurisdiction over state law claims.

3. Venue is appropriate in this judicial district under 28 U.S.C. §1391(b) because the events that gave rise to this Complaint occurred in this district.

#### **PARTIES**

4. Plaintiff is a citizen of the United States and resides in the County of \_\_\_\_\_, State of **[Michigan]**, which is in this judicial district.

5. Defendant \_\_\_\_\_ **[Individual’s Name]** is the Director of the **[Michigan Department of Community Health (“MDCH”)]**. Defendant \_\_\_\_\_ **[director’s name]** is sued in **[his/her]** official capacity as Director of **[MDCH]**. As such, **[he/she]** has a duty to insure that the state’s federally funded Medicaid program(s) are administered in accordance with federal and state law.

6. Defendant **[MDCH]** is the single state agency responsible for the administration of the Medicaid program, Title XIX of the Social Security Act, in **[Michigan]**. **[MDCH]** has contracted with Defendant \_\_\_\_\_ **[Waiver Agency]** to provide Medicaid covered services to Medicaid eligible clients in \_\_\_\_\_ County, such as Plaintiff.

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*[If applicable]* [County Organization] in turn has contracted with \_\_\_\_\_ [Service Provider] to assess and arrange for Medicaid covered mental health services for [County Organization]'s clients.

7. [Defendant/Defendants] [is/are] a public entity for the purposes of the ADA pursuant to 42 U.S.C. §12131(1), and is located in the County of \_\_\_\_\_, State of [Michigan], which is in this judicial district. [Defendant/Defendants] provide programs and/or activities receiving federal financial assistance acting under the color of state and federal law.

### GENERAL ALLEGATIONS

8. The Federal Medicaid statute, Title XIX of the Social Security Act, is codified at 42 U.S.C. § 1396 *et seq.* It authorizes the establishment by states of medical assistance programs for low income individuals who meet certain eligibility requirements. These medical assistance programs are jointly funded by the federal and state governments, and are designed by the states within the framework of options and requirements established under the Medicaid statute.

9. Pursuant to the federal statutory scheme, when an application for Medicaid benefits is filed with the single state agency responsible for administering the Medicaid program(s), such assistance shall be furnished with reasonable promptness to all eligible individuals. 42 U.S.C. §1396a(a)(8). Once individuals have been determined eligible, the state agency must continue to furnish Medicaid services until the recipient is found to be ineligible. 42 C.F.R. §435.930(b).

10. The Federal Medicaid statute, as well as the [Michigan State Plan] approved by the Federal Medicaid agency, lists services that must be provided to eligible persons. Such

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services include \_\_\_\_\_ **[Name of Waiver]** services (“Alternative Services”) for persons who would otherwise require institutional care. 42 U.S.C. §1396a(a)(10)(A)(ii)(VI).

11. The Federal Medicaid statute further requires that an individual eligible for Alternative Services be able to freely choose such services provided in **[his/her]** home or community setting as opposed to institutional services. 42 U.S.C. §1396n(c)(2)(C) and (d)(2)(C).

12. Title II of the ADA, found at 42 U.S.C. §§12131-12134, extends to state and local governments the non-discrimination provisions of the Rehabilitation Act. It requires that their services, programs and activities of state and local governments be administered in the most integrated setting appropriate to the needs of qualified individuals with disabilities.

13. Plaintiff is a \_\_\_\_\_-year-old **[Woman/Man]** with the following need for long term care via Medicaid services: \_\_\_\_\_, \_\_\_\_\_, and \_\_\_\_\_ **[List/description of Disabilities/Long term care needs]**.

14. As a result of Plaintiff’s condition(s) \_\_\_\_\_ **[describe/list what effects Plaintiff’s age/disabilities have on her/him]**.

15. Plaintiff is eligible to be a Medicaid beneficiary of the \_\_\_\_\_ waiver program **[Name of Waiver Program]** (“Program”). Under the Program, Plaintiff is entitled to receive \_\_\_\_\_ **[Scope, amount and duration of Services Plaintiff Receives or should Receive]**.

16. Plaintiff meets the essential eligibility requirements for the receipt of services or the participation in **[Defendant’s/Defendants’]** Program.

17. On or about \_\_\_\_\_ **[Date]**, Plaintiff applied to be a participant in **[Defendant’s/Defendants’]** Program.

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18. On or about \_\_\_\_\_ [Date], [Defendant/Defendants], acting under the color of state and federal law, denied Plaintiff's request to be a participant in [Defendant's/Defendants'] Program, [If Applicable] placing Plaintiff on a "waiting list."

19. [Defendant's/Defendants'] administration of the Program limits the availability of the Alternative Services.

20. Without the Alternative Services, Plaintiff will have no choice but to move into an institution and/or nursing home.

**COUNT I**  
**VIOLATION OF 42 U.S.C. §1983**

21. Plaintiff incorporates and restates each of the above paragraphs as if fully set forth herein.

22. [Defendant/Defendants] [has/have] deprived Plaintiff of [his/her] federal constitutional and/or statutory rights by failing and refusing to provide Plaintiff with the home care services prescribed in [his/her] \_\_\_\_\_ care plans.

23. [Defendant/Defendants] [has/have] acted under the color of state law when [Defendant/Defendants] deprived Plaintiff of [his/her] federal rights, property interests and otherwise discriminated against Plaintiff based upon Plaintiff's disability.

24. As a direct and proximate result of [Defendant's/Defendants'] violation of 42 U.S.C. §1983, Plaintiff has sustained injuries and damages. [If applicable list injuries and damages suffered].

**COUNT II**  
**VIOLATION OF THE MEDICAID STATUTE AND REGULATIONS**

25. Plaintiff incorporates and restates each of the above paragraphs as if fully set forth herein.

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26. The failure of **[Defendant/Defendants]** to provide Plaintiff with the Alternative Services violates provisions of the Federal Medicaid statute and regulations including, without limitation, the following:

- (a) The requirement of 42 U.S.C. §1396a(a)(8) that Medicaid assistance be furnished with reasonable promptness to eligible individuals.
- (b) The requirement of 42 C.F.R. §435.930(b) that once an individual has been found eligible for Medicaid services, the state agency must continue to provide such services until the recipient is found ineligible.
- (c) The requirement of 42 U.S.C. §1396a(a)(10)(A)(ii)(VI) that the Alternative Services be made available to persons who would otherwise be eligible for institutional care.
- (d) The requirement in 42 U.S.C. §1396n(c)(2)(C) and (d)(2)(C) that an Alternative Services eligible beneficiary be able to freely choose to receive medical assistance at home or in a community setting as opposed to receiving institutional care.

27. As a direct and proximate result of **[Defendant's/Defendants']** unlawful discrimination, Plaintiff has sustained injuries and damages. *[If applicable list injuries and damages suffered]*

**COUNT III**  
**VIOLATION OF THE [MICHIGAN] \_\_\_\_\_ STATE PLAN,**  
**THE \_\_\_\_\_ STATUTE AND REGULATIONS**

28. Plaintiff incorporates and restates each of the above paragraphs as if fully set forth herein.

29. The failure of Defendant **[MDCH]** to provide Plaintiff with the Alternative Services prescribed in **[his/her] \_\_\_\_\_ [Name of Plan]** care plan(s) violates provisions of **[Michigan]** state law including, without limitation, the following:

- (a) The requirement of \_\_\_\_\_ **[Statute Cite]** that long term care services at home or in a community setting be made available to persons at risk of institutionalization who choose them as an alternative to nursing facility services.

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(b) The agreement in the **[Michigan]** State Plan that Alternative Services be provided to eligible persons.

30. As a direct and proximate result of **[Defendant's/Defendants']** unlawful discrimination, Plaintiff has sustained injuries and damages. *[If applicable list injuries and damages suffered]*

**COUNT IV**  
**DISCRIMINATION BASED ON DISABILITY**  
**(Title II of ADA)**

31. Plaintiff incorporates and restates each of the above paragraphs as if fully set forth herein.

32. Plaintiff is a “qualified individual with a disability” as defined in 42 U.S.C. §12131(2).

33. The ADA and its implementing regulations require that the Alternative Services be made available in the community rather than in institutions where to do so will meet the needs of qualified individuals with disabilities, such as Plaintiff.

34. Plaintiff has been denied and excluded from the benefits of **[Defendant's/Defendants']** Program, which would provide Plaintiff a less confining program that satisfies Plaintiff's needs.

35. As a result of **[Defendant's/Defendants']** denial and exclusion of Plaintiff from the Program, **[Defendant/Defendants]** violated the ADA by discriminating against Plaintiff in a number of ways, including without limitation, the following:

- (a) By reason of Plaintiff's disabilities, age and need for long-term care services;
- (b) The under-funding of the Program compelling institutionalization or placement in a nursing home, thus negating a meaningful choice for Plaintiff; by denying a waiver to Plaintiff, the Defendant is failing to reasonably accommodate the Plaintiff. Denial of long-term care for medically needy Medicaid beneficiaries in community based settings violates the ADA as the

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**[Defendant's/Defendants']** can not show that providing these services is a fundamental alteration of Michigan's Medicaid program. *Townsend v. Quasim* 328 F3d 511 (9<sup>th</sup> Cir. 2003)

- (c) Providing services Plaintiff requires only in a segregated setting, as opposed to the "most integrated setting" appropriate to the needs of Plaintiff;
- (d) **[Defendant's/Defendants']** administration of the Program limits the availability of Alternative Services based on the severity of need or disability; and
- (e) Denying Plaintiff the equal/same opportunity to receive the benefit(s) of **[Defendant's/Defendants']** programs/activities that are available to other qualified individuals. It is not a fundamental alteration of the long term care system to accommodate the Plaintiff's request to receive services in the least restrictive setting.

36. **[Defendant's/Defendants']** actions violate the *Olmstead* ruling by the undue institutionalization of Plaintiff where a less confining service can satisfy Plaintiff's needs, and failure of **[Defendant/Defendants]** to administer the services, programs and activities in the most integrated setting appropriate to the needs of Plaintiff.

37. As a direct and proximate result of **[Defendant's/Defendants']** unlawful discrimination, Plaintiff has sustained injuries and damages. *[If applicable list injuries and damages suffered, including but not limited to needless isolation/segregation.]*

#### **COUNT V** **VIOLATION OF THE REHABILITATION ACT**

38. Plaintiff incorporates and restates each of the above paragraphs as if fully set forth herein.

39. Plaintiff is a "disabled/handicapped" individual as defined in 29 U.S.C. 705.

40. The Rehabilitation Act and its implementing regulations require that **[Defendant's/Defendants']** administer programs/activities in the most integrated setting

appropriate to the needs of qualified handicapped/disabled persons. 28 C.F.R. §41.51 and 45 C.F.R §84.4.

41. Plaintiff has been denied and excluded from the benefits of **[Defendant's/Defendants']** Program, which would provide Plaintiff a less confining program that satisfies Plaintiff's needs.

42. As a result of **[Defendant's/Defendants']** denial and exclusion of Plaintiff from the Program, **[Defendant/Defendants]** violated the Rehabilitation Act by discriminating against Plaintiff in a number of ways, including without limitation, the following:

- (a) By reason of Plaintiff's disabilities, age and need for long-term care services;
- (b) The underfunding of the Program compelling institutionalization or placement in a nursing home, thus negating a meaningful choice;
- (c) Providing services Plaintiff requires only in a segregated setting, as opposed to the "most integrated setting" appropriate to the needs of Plaintiff;
- (d) Defendant's administration of the Program limits the availability of Alternative Services based on the severity of need or disability; and
- (e) Denying Plaintiff the equal/same opportunity to receive the benefit(s) of **[Defendant's/Defendants']** programs/activities that are available to other qualified individuals with disabilities.

43. As a direct and proximate result of **[Defendant's/Defendants']** unlawful discrimination, Plaintiff has sustained injuries and damages. *[If applicable list injuries and damages suffered]*

**COUNT VI**  
**DISCRIMINATION BASED ON DISABILITY (PDCRA)**

44. Plaintiff incorporates and restates each of the above paragraphs as if fully set forth herein.

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45. Plaintiff's developmental disabilities that substantially limits one or more major life activities unrelated to **[his/her]** ability to utilize and benefit from a place of public accommodation or public service, constitute a *disability* by and within the meaning of the PDCRA, M.C.L. §37.1103(d).

46. **[Defendant/Defendants]** violated the PDCRA, M.C.L. §37.1302, by discriminating against Plaintiff upon **[his/her]** application to be a participant in the Program in a number of ways including, without limitation, the denying Plaintiff the full and equal enjoyment of the goods, services, facilities, privileges, advantages, and accommodations of a public service because of a disability that is unrelated to Plaintiff's ability to utilize and benefit from the goods, services, facilities, privileges, advantages, or accommodations or because of the use by Plaintiff of adaptive devices or aids (M.C.L. §37.1302(a)).

47. Plaintiff's *disability* was a determining factor in **[Defendant's/Defendants']** decision to deny and preclude Plaintiff from being a participant in the Program.

48. As a direct and proximate result of **[Defendant's/Defendants']** unlawful discrimination, Plaintiff has sustained injuries and damages. *[If applicable list injuries and damages suffered]*

WHEREFORE, Plaintiff requests that this Court enter judgment against **[Defendant/Defendants]** providing the following relief:

- (a) Compensatory damages in whatever amount in excess of \$ \_\_\_\_\_, exclusive of costs and interest, that Plaintiff is found to be entitled;
- (b) Punitive/exemplary damages against **[Defendant/Defendants]** in whatever amount, exclusive of costs and interest, that Plaintiff is found to be entitled;
- (c) An order placing Plaintiff in the position that **[he/she]** would have been in had there been no violation of **[his/her]** rights;

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- (d) An order enjoining/restraining **[Defendant/Defendants]** from further acts of discrimination or retaliation;
- (e) An award of interest, costs, and reasonable attorney's fees;
- (f) Any and all other remedies provided pursuant to 42 U.S.C. §1983, the Federal Medicaid statute and regulations, the ADA, the Rehabilitation Act and the PDCRA;
- (g) Take other appropriate nondiscriminatory measures to overcome the above described discrimination; and
- (h) such other and further relief as the Court deems appropriate.

**[Firm Name]**

By: \_\_\_\_\_  
**[Attorney name(s)]**  
Attorney(s) for Plaintiff  
**[Address and phone number]**

**Sample Complaint drafted by Patricia E. Kefalas Dudek and Victor A. Veprauskas IV**  
*victor/misc/ada sample complaint*

This Complaint is intended to provide a general sample complaint for filing an action in U.S. Federal District Courts. This sample Complaint is not intended to render legal advice. Other statutes, case law, as well as the facts and circumstances of each case greatly affect the analysis of any given matter. Consultation with legal counsel is recommended to provide individualized advice and compliance with applicable laws and statutes.

# Policy Research Brief

RESEARCH AND  
TRAINING CENTER  
ON COMMUNITY LIVING  
UNIVERSITY OF MINNESOTA

## Costs\* and Outcomes of Community Services for Persons with Intellectual and Developmental Disabilities

*This Policy Research Brief reviews available research on the costs and outcomes of community service provision for people with intellectual disabilities (or "mental retardation") and developmental 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, and Roger Stancliffe at rogers@localnet.com.au.*

### ■ Introduction

In recent decades, formal paid support services for people with intellectual disabilities (or "mental retardation") and developmental disabilities (ID/DD) have shifted dramatically from institutional to community settings. Between 1967 and 2002, there was an 80.5% reduction in people with ID/DD living in state developmental disability (DD) and psychiatric institutions, from 228,500 to 44,610 (Prouty,

\*The term "costs" is used throughout this review in many instances where the term "expenditure" might be more appropriate. "Cost" is often defined by economists to include contributions to supporting an individual to which a monetary value can be affixed (e.g., the actual fare plus the public services of the public bus ride an individual takes to work, or the income cost for the time a parent takes off work to accompany an adult child to the dentist). "Expenditures," on the other hand, are understood to mean money paid out. For the most part, this review is about what economists would call "expenditures," but in seeking to speak to non-technical readers the authors have also used the common term "costs" throughout.

Smith, & Lakin, 2003). Many factors have contributed to this rapid change, including costs that are consistently 5% to 27% higher in institutions for comparable intensities of service (Stancliffe et al., in press) to achieve consistently poorer outcomes (Kim, Larson, & Lakin, 2001). Equally important have been social and legal commitments to the "most integrated setting feasible" as conveyed in the Americans with Disabilities Act and defined in *Olmstead et al v. L.C. et al* (527 U.S. 581) and "with the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives and to fully participate in and contribute to their communities..." as conveyed in the Developmental Disabilities Assistance and Bill of Rights Act (42 USC 15001(101[a])). One essential outcome of deinstitutionalization was the growth of a comprehensive range of decentralized, flexible community services. It is the financing, cost, and outcomes of these community services that is the focus of this *Policy Research Brief*.

### ■ Method

This review examined research related to the financing, costs, and outcomes of community services for people with intellectual disabilities, especially residential services. The authors examined over 80 U.S. studies published from 1980 onwards, as well as a small number of policy-relevant studies from the United Kingdom (U.K.) and Australia.

A summary of research on policy issues affecting persons with developmental disabilities. Published by the Research and Training Center on Community Living, Institute on Community Integration (UCEDD), College of Education and Human Development, University of Minnesota.



Research was selected primarily for its relevance to key policy issues such as a) the costs and outcomes of different types of residential services, b) the relation between funding level and service recipients' support needs, c) individual budgets, d) family support, and e) economies of scale. More detailed information on these and related issues may be found in Stancliffe and Lakin (in press a ).

## ■ Findings

### Challenges in Financing Long-Term Services and Supports (LTSS)

In the United States, federal, state, and local governments spent almost \$35 billion in fiscal year (FY) 2002 on non-educational services for persons with ID/DD (Braddock, Rizzolo, Hemp, & Parish, in press; Rizzolo, Hemp, Braddock, & Pomeranz-Bssley, 2004). Almost 80% of this amount was used to fund community services, with the remainder financing institutional services. In FY 2002, federal and state Medicaid ICF/MR and Home and Community Based Services (HCBS) programs exceeded \$24 billion in total long-term care expenditures (Prouty et al., 2003). The recent budget crises faced by the majority of states in the U.S. have shown how important it is to have information on costs and outcomes and how rarely such information is available when needed. It is now better understood that there are undesirable consequences of not reforming ineffective, inappropriate or excessively costly services. These include limited (or nonexistent) access to needed services by those who are unserved, underserved or poorly served, and wholesale across-the-board funding cuts affecting efficient and effective services equally with inefficient and ineffective services. A focus on cost should not imply that lower cost is self-evidently better, or that cost outweighs other considerations. For example, Emerson, Robertson, Hatton, Knapp and Walsh (in press) found that institutional services in the UK, unlike the U.S., cost less than community services, but they concluded that the additional expenditure on community services was warranted in the light of the consistently better outcomes associated with community services.

Several other financing challenges are influencing expenditures on long-term services and supports (LTSS), such as:

- **Utilization rate of ID/DD services is rising.** The proportion of the U.S. population receiving services has been increasing steadily. Substantially increased life expectancy among people with ID/DD (Janicki, Dalton, Henderson, & Davidson, 1999) means that people who receive services will receive them for more years than ever before. The result is a demand for services that is increasing more rapidly than would be expected based on general population growth alone. Nationally,

between 1991 and 2002, the number of persons receiving residential services grew by 105,446 (36.7%). During this period, the service utilization rate increased 19.3% from 114 per 100,000 of total population in 1991 to 136.2 per 100,000 in 2002 (Prouty et al., 2003). Despite growing financial commitments to services and increased utilization of those services, in 2002 there were almost 60,000 people waiting for residential services.

- **Waiting lists.** People on waiting lists reflect an ongoing national crisis in equality and access to services (Hemp, Braddock, Parish, & Smith, 2001; Lakin, 1998). In June 2003, states reported an estimated 73,000 persons with ID/DD waiting for community residential supports (Prouty, Smith, & Lakin, 2004). By 2004, more than 30 class action lawsuits that were related to issues of access to community supports had been filed (Smith, 2004). *Boulet et al. v. Cellucci et al.* was one of the first of these lawsuits to be resolved. Its settlement agreement committed Massachusetts to spend \$355.8 million between 2002-06 to expand community services (Smith, 2001).
- **Federal cost sharing.** Rizzolo et al. (2004) identified state expenditures on ID/DD services that are currently unmatched by programs offering federal cost sharing as one important but underutilized source of funding for states to draw on to meet the needs of people on waiting lists. Hemp et al. (2001) noted that \$4.9 billion in unmatched state expenditure was applied to state ID/DD systems in 1998. Using unmatched state funds to match additional Medicaid HCBS funding represents one important avenue by which many states could expand their community ID/DD services.

Challenges to financing LTSS arise from current constraints on state revenues and expenditures, and from growing demand for services as indicated by rising utilization rates, waiting lists, and associated lawsuits. Ensuring that state expenditures are matched through federal cost sharing provides one means of financing an expansion of services. Careful examination of the costs and outcomes of existing services, and of current funding arrangements, is essential for effective use of public funding and to assure that LTSS recipients enjoy the greatest positive benefit.

### Costs and Outcomes of Different Service Types

In a certain sense, Medicaid ICF/MR and HCBS programs are ways to finance services. In another sense, however, they represent service models of substantial distinction. ICFs/MR are highly regulated congregate settings in which no fewer than four and as many as several hundred people live according to rules established by the federal government. HCBS on the other hand, allows states great flexibility in the settings, rules, and types of services and supports

financed. Medicaid expenditures are disproportionately higher for persons in ICFs/MR than for HCBS recipients. The 2002 average annual expenditure for ICF/MR residents was \$85,746 as compared to \$37,816 for each HCBS recipient (Prouty et al., 2003). Lakin, Hewitt, Larson, and Stancliffe (in press) and Hewitt, Larson, and Lakin (2000) reported that, in Minnesota, combined packages of health, social, and vocational supports for HCBS service recipients were about 78% of the service cost for ICF/MR residents. Conroy (1998) found that HCBS waiver service costs in California were 74% of the ICF/MR costs for groups with similar characteristics. Some of these comparisons were complicated by differences in characteristics of service recipients and/or the array of services provided. Even so, ICF/MR services are consistently reported, on average, to cost more.

Increased costs can be justified if significantly better outcomes are associated with additional expenditures in ICFs/MR. On the contrary, however, specific comparisons between community ICFs/MR (with 15 or fewer residents) and HCBS-funded residences have shown better self-determination, integration, quality of life, challenging behavior, and adaptive behavior outcomes in HCBS settings (Conroy, 1998; Stancliffe, Aberly, & Smith, 2000; Stancliffe, Hayden, Larson, & Lakin, 2002).

Overall, the available cost and outcome studies are consistent in their findings that ICFs/MR are less cost-effective than HCBS-financed residential settings. Consistent with cost-effective use of public resources, the numbers of residents in community ICFs/MR were static (a 1% national decline) between 2001 and 2002, whereas persons living in non-family residential arrangements with HCBS financing grew rapidly (a 15% national increase) between 2001 and 2002 (Prouty et al., 2003).

Comparisons between group homes and semi-independent living have shown more favorable outcomes in semi-independent settings (Burchard, Hasazi, Gordon, & Yoe, 1991; Stancliffe, in press; Stancliffe, Aberly, & Smith, 2000; Stancliffe & Keane, 2000). Not surprisingly, service costs were substantially lower for the semi-independent settings, which have part-time staffing as compared with the 24-hour paid staffing typical of group homes (Stancliffe & Keane, 2000). Available research on supported living in the U.S. (Howe, Horner, & Newton, 1998) and the UK (Emerson et al., 2001; Emerson et al., in press) has reported similar costs to traditional community living services. Supported living is, by definition, focused on assisting people to live out lifestyles of their own choice in homes of their own, so it is not surprising that these same studies have found better outcomes on resident choice and community participation than in traditional community congregate settings.

Overall, these findings suggest that more individualized services, such as semi-independent living and supported living, are more cost-effective than traditional community living services such as group homes.

## Needs-Based Funding

Allocating funding in a manner that equitably meets the needs of service users is a basic value expected of effective service systems. Funding distribution is expected to be fair, consistent, and based on valid methods for determining who gets what levels of funding and support. To date, support needs have mostly been framed in terms of individual characteristics, so that persons with fewer self-care skills, more challenging behavior, or more serious health problems are considered to need, and are assumed to receive, more support. Such individuals are also assumed to require greater per-person expenditure when supports are provided by paid staff. Despite such assumptions, long-term service and support systems frequently have not been operated or financed on the basis of individual needs or preferences (see Stancliffe & Lakin, 1998). Financing of congregate facilities has often been based on rate schedules and facility operating costs, cost caps, local negotiation with service providers, and historical reimbursement rates, with little specific attention to the individual needs and characteristics of persons served.

Past research on different state service systems has reported varying findings concerning the association between expenditures and individual characteristics. Results ranged from a weak, inconsistent or non-existent association in Michigan, Nebraska, and New Hampshire (Ashbaugh & Nerney, 1990; Nerney, Conley, & Nisbet, 1990) as well as Minnesota (Stancliffe & Lakin, 1998), to a more moderate association in Pennsylvania (Jones, Conroy, Feinstein, & Lemanowicz, 1984), and a very strong association in South Dakota (Campbell & Heal, 1995). These mixed findings suggest that funding for services can be directly linked to individualized support needs, but that such practices are far from universal.

Current research on needs-based funding includes studies in Minnesota and Wyoming. In FY 1996, Minnesota implemented a four-level Waiver Allocation Structure (WAS) to assign funding for *new* entrants to the state's HCBS program in an attempt to make funding more needs based. Using assessed personal characteristics, the WAS assigns each individual to one of four levels of HCBS funding. This amount is provided by the state to the county, from which the county contracts with providers to deliver services to the person, but with no requirement that the amount of funding provided by the state to the county actually be budgeted for that particular person's services. That is, counties can spend more or less than they are allocated for an individual when purchasing that individual's support. Analysis of Minnesota's HCBS expenditures for FY 1998 revealed a relatively weak relation between the four WAS funding levels and actual expenditures for individual HCBS recipients (Lakin et al., in press). Minnesota's funding policy is needs based with regard to allocation to counties, but it has not resulted in a

funding system that is needs based with regard to allocation to individuals. The WAS accounted for only 8.4% of variability in HCBS expenditures for individuals assessed under the WAS system. Importantly, Lakin et al. (in press) found that, when employed in addition to the WAS categories, recipients' personal characteristics accounted for an additional 15.3% of variability in individual HCBS expenditures. Adaptive behavior and challenging behavior were the strongest predictors. In other words, the same characteristics that were used to place people into one of the four WAS categories, when reemployed as *continuous* scales (rather than a few discrete levels), were much more predictive of individual HCBS expenditures in Minnesota than the assignment of people to one of four WAS categories.

Fortune et al. (in press) have described the problems experienced in the 1990s in Wyoming with a system involving five payment levels, somewhat similar to Minnesota's WAS levels. Subsequently, Wyoming moved to an individualized funding model based on each person's objectively assessed individual characteristics and his or her service utilization – the DOORS model – which directly provides a *unique* Individual Budget Amount (IBA) to pay for that individual's services. This system is not restricted to a particular number of discrete funding levels. Compared to the situation prior to the introduction of DOORS, when the five-level system was used, the proportion of variability in individual funding associated with individual characteristics rose from 37% to 47%, and the proportion of variability explained by the total DOORS model increased from 52% to 75%. That is, there was a substantial increase in the association between individual service users' assessed support needs and the amounts of funding provided to meet those needs, indicating that the DOORS model successfully made Wyoming's HCBS funding system more needs based.

The different outcomes in Wyoming and Minnesota suggest that funding is most effectively needs based when:

- a) needs-based funding systems are applied to *all* recipients, not just those entering the system for the first time;
- b) continuous *individualized* funding amounts are provided (rather than a small number of discrete funding levels);
- c) a specified amount allocated to pay for services is received *by the individual* rather than infusing it into an overall pool to be managed by an intermediate agency for multiple service recipients; and
- d) variations in allocated amounts reflect different circumstances (e.g., people living with family members versus in residential settings; children who are enrolled in public schools). Funding arrangements based on individual assessment of support needs offer a rational and equitable basis for allocation of public money. However, in a national survey of individual budgeting methodology, the majority of states reported that they did not consider their current funding allocation methods to be data based (Moseley, Gettings, & Cooper, in press).

States participating in the Medicaid HCBS Independence Plus option for self-directed services purchased using

individual budgets are required to use consistent, data-based methods to determine individual budgets. The further development, evaluation, and refinement of procedures to establish rational, reliable, and appropriate levels of funding for individuals needing support will continue to be an important task for researchers and policymakers. Existing systems, such as Wyoming's DOORS model, and existing instruments such as the American Association on Mental Retardation's *Supports Intensity Scale* (Thompson et al., 2004), may contribute to more universal and more effective approaches to individual need-based budget allocations.

### Individual Budgets

A desire for more flexible, individualized, consumer-directed services, together with the move toward needs-based funding, has been reflected in the rapid increase in availability of "individual budgets" for use in purchasing services and supports. An *individual budget* is "A mechanism that establishes an amount of funding available for an individual with disabilities to direct and manage the delivery of services she or he is authorized to receive. The amount of the individual budget is derived from a data-based methodology, and is open to inspection and input from the individual receiving support" (Moseley et al., in press). Ideally, an individual budget is needs based, flexible, and portable (i.e., not tied to a particular service type or to a specific service provider), and is intended to provide service users and their families with significant control over services and supports as well as sufficient resources to purchase what they need (Moseley, 2001). Within the traditional facility-based, regulated long-term service and support systems, funding is often based on the costs of providing services to a certain size group of people in a particular setting. Such funding is rarely flexible or portable because it is not associated with specific individuals or their needs. The amount of the total funding required to support a particular person in the setting is rarely known, even though different people may receive very different amounts of assistance.

Individual budgets have moved from being a policy experiment in the 1990s to becoming a mainstream funding option in the early 21st century. In 2003, Moseley et al. (in press) conducted a national survey and received responses from 43 states. They found that an individual budget option was in place in 75% of these states. In some states, such as Wyoming, the individual budgeting approach is applied to *all* (HCBS) consumers, but in other states individual budgets are provided as an option or are only open to some service users (see Moseley et al., in press). One consequence of the latter approach is that individual budgets may be more accessible to some service users than others. For example, service users with strong advocates may obtain greater access to individual budgets. Stancliffe and Lakin (in press<sup>b</sup>) investigated whether personal characteristics, family involvement or living arrangements distinguished between

service users with and without an individual budget. These investigators found that, for a sample of service users in Michigan, individual budget availability was equitable in that it was not related to service users' personal characteristics or family involvement. However, individual budgets were more frequently used by persons living in smaller residential service settings and in their own home. Given the cross-sectional nature of this study, it was not possible to determine whether this finding was the result of individual budget availability (i.e., consumers used their individual budget to *move* to such living arrangements) or whether individual budgets were made available more often to those *already* living in smaller settings or their own home. Future development of individual budget policy and practice will need to take into account equity of access to individual budgets for all service users.

The rapid increase in availability of individual budgets has confronted state officials with the need to develop methodologies for equitable allocation of funding. Need-based funding methodologies, such as the Wyoming DOORS model discussed previously, appear to provide a viable and equitable approach. Moseley et al. (in press) reported that, among the states offering individual budgets, about one-third used standardized tools to assess support needs and data-based procedures for calculating the amount of funding to be allocated to the individual. Once this amount is determined, individual planning approaches are employed to decide how these funds will be used to meet individual needs. In about two-thirds of states with an individual budgeting option, a more developmental approach is taken. Individual budget amounts are established within a planning process that includes identifying individual service and support needs and determining a budget needed to buy these service and supports (Moseley et al., in press). States may use individual budgets as a means to manage overall disability expenditures by establishing expenditure limits for individual recipients, sometimes at a notable "discount" on the estimated or previously experienced amounts that traditional services cost for the individual (e.g., Head & Conroy, in press; Moseley et al., in press). While Wyoming's system of Individual Budget Amounts (IBAs) is based substantially on each person's individual characteristics, other approaches have based the amount on the characteristics of service providers and/or costs of current services and supports. Campbell et al. (in press) argue that approaches focused on service providers result in undesirable outcomes, such as severely limiting portability of funding and constraining the ability to respond to an individual's specific needs. The individual and systemic consequences of different approaches to individual budgeting will assume growing importance as individual budgets become more widespread.

### Evidence on Costs and Outcomes with Individual Budgets

Pilot projects on consumer-directed services (CDS) (often referred to as "self-determination") in various states were funded by the Robert Wood Johnson Foundation in the 1990s. A key feature of these projects was the provision of individual budgets with which to purchase services and supports, with the intent that control over the services and supports would rest with people receiving those services and their family and friends (Moseley, 1999). Conroy and Yuskaskas' (1996) study of the original Robert Wood Johnson Foundation funded self-determination project in New Hampshire found significant improvements in outcomes after 18 months of self-determination interventions. Participants had more control over many areas of their lives (e.g., spending own money, time use, choice of house), increased quality of life in numerous areas (e.g., health, relationships), more invited and unpaid people on planning teams, less challenging behavior, and more productive behavior. These positive outcomes were achieved at a significantly lower cost (a 12% to 15% lower inflation-adjusted expenditure) than before program participation. However, it was notable that, in New Hampshire, control over many service-related issues (such as choice of case manager, choice of people to live with, type of work or day program, choice of house or apartment, amount of time spent at work/day program) remained the least available choices to service users and their families and did not change significantly over time. This suggests that consumer control over services was not achieved to the extent expected in New Hampshire.

More recently, Head and Conroy (in press) found significant improvements in consumer choice and control, quality of life, satisfaction, and community participation following implementation of CDS in Michigan. The largest changes in choice and control were in major service-related areas such as hire and fire direct support staff, choice of agency support person, choice of people to live with, choice of house or apartment, and choice of case manager. In Michigan, a substantial transfer of control over services had taken place from staff and other professionals to individual consumers and their families after three years of CDS. In addition, Head and Conroy reported that, from 1998 to 2001, average public costs (adjusted for inflation) for study participants *decreased* by 16%, although not uniformly across all participants. Those with the highest initial costs in 1998 under traditional funding and service delivery arrangements tended to have the largest decreases in expenditures following introduction of an individual budget and consumer-directed services, but a number of individuals, who tended to have lower pre-CDS expenditures, had *increases* in expenditures during the three-year period.

These findings suggest that better outcomes can be achieved at slightly lower cost through provision of

individual budgets and other elements of consumer-directed support. Still, there remains relatively little published research in this area and it will be important to continue to evaluate such initiatives to tease out those aspects of interventions that are causally related to changes in outcomes and costs. For example, at present there is little published information about how services and supports change following the availability of an individual budget and whether specific service changes are associated with changes in outcomes. Stancliffe and Lakin (in press<sup>b</sup>) found that small scale, individualized living arrangements were much more strongly related to the person's degree of choice and control than was their individual budget status (whether or not they had an individual budget). This suggests that the choices of services and supports made on the basis of control of one's budget may be particularly important. Such a finding does not diminish the importance of budgetary control, but reminds us that it is not opportunity that creates outcomes, it is what one does with opportunity. It will also be important to understand better the existing "market" for CDS – that is, which individuals and families are most interested in and able to benefit from such opportunities – so that potential use may be gauged and the preparation and support needed to make CDS more widely available can be designed and tested.

### Family Support

Most people with ID/DD live in the family home and are supported by their immediate family. Fujiura (1998) estimated that in 1991, 61% of U.S. individuals with ID/DD lived with family members, with only 11% in the formal long-term ID/DD residential service system. For some time, there has been widespread agreement that children and youth with ID/DD should live with family (Roseneau, 1990; Taylor, Lakin, & Hill, 1989) and there is currently a major national commitment to "Support families as the most permanent unit of development, protection and assistance" (National Goals Conference, 2003, p. 4). The family home continues to be the place of residence for the majority of people with ID/DD, and immediate family members are the primary caregivers for these individuals. Despite this situation, in 2000, only 4% of expenditure of state ID/DD agencies was used for family support (Parish, Pomeranz-Essley, & Braddock, 2003). Although vastly fewer resources are available to families than to users of residential services, this disparity is diminishing, with an 85% real increase in family support expenditures between 1996 and 2000 associated with a rapid growth in both the number of families receiving support and the amount of support provided to each family (Parish et al.). In fact, in 2001 there were more recipients of family support (452,000) than of residential services (388,000) (Lakin, Prouty, Polister, & Coucouvanis, 2003).

Herman (1991, 1994) examined the impact of a family cash subsidy program in Michigan for families with a child with a developmental disability. Families reported satisfaction with the program and indicated that the subsidy helped to improve family life, ease financial worries, and reduce stress. Importantly, families used the subsidy for the types of services they said were needed.

Between 1977 and 1997, the number of children and youth 21 years and younger with ID/DD living in out-of-home residential settings for persons with ID/DD (excluding generic foster care) decreased from 91,189 to an estimated 25,841 (Lakin, Anderson, & Prouty, 1998). This is no doubt a result of family support in various forms including respite care, personal assistance, cash subsidies, and others. The much greater cost of out-of-home placements supports the argument that it is less expensive for taxpayers to invest in family support than to pay for costly out-of-home services. The challenge is, of course, the targeting of the benefits in type and cost to those who need them to maintain their children at home.

Formal family support services, such as respite care, personal assistance, and parent education have tended to be agency directed. Growing interest in consumer-directed services has also influenced a number of states to implement consumer-directed family support services. Caldwell and Heller (2003) examined a consumer-directed family support program in Illinois. They found that more control by families of respite and personal assistance services was linked to increased satisfaction with services, more community participation by the person with a developmental disability, less staff turnover, and more hours per week of employment for mothers. This last finding represents an important outcome in the context of the substantial economic costs and reduced employment opportunities experienced by families with a member with a disability (Anderson, Larson, Lakin, & Kwak, 2002; Lewis & Johnson, in press). Caldwell and Heller (2003) also reported that families tended to hire people they knew (friends, neighbors, other relatives living outside the immediate home) to provide respite and personal assistance. Hiring relatives was associated with increased community participation by the person with ID/DD. In short, consumer-directed family support was shown to have benefits for both families and people with ID/DD.

### Economies of Scale

Service policy and planning have been influenced by the widespread assumption that economies of scale operate in human services, and that the congregation of greater numbers of service recipients in a setting will tend to yield lower per-person costs. Larger scale public institutions and community ICFs/MR has been defended as responsible fiscal policy because of presumed economies of scale (Erb, 1995). Similarly, small individualized living arrangements

have, until recently, tended to be limited largely to individuals requiring relatively low levels of support, partly because high levels of support were believed to be too costly to provide in small service settings.

Intellectual disability services are staff intensive. As a result, human services do not behave like manufacturing industries with regard to "economies of scale." Actual evidence for economies of scale in ID/DD services has been equivocal and has frequently contradicted the expectation that smaller-scale services will be more costly. The recurring U.S. finding that institutional services have higher per-person costs than much smaller scale community services directly contradicts the notion of economies of scale (Campbell & Heal, 1995; Stancliffe, Lakin, Shea, Prouty, & Coucouvanis, in press). Rhoades and Altman (2001) found that costs *increase* as residence size increases. In Minnesota, Stancliffe and Lakin (1998) found medium-sized community residential settings (with 5-6 people) to be more costly than either smaller or larger community settings in the 1-15 person size range. Howe, Horner, and Newton (1998) found no difference in the costs of supported living and traditional community living in Oregon, even though the number of residents per setting averaged 1.6 and 6.9 respectively.

Nerney et al. (1990) reported some U.S. evidence of diseconomies of very small scale, but their findings appear to be model dependent and only evident among very small group homes with 24-hour paid staffing. Felce and Emerson (in press) concluded that, in UK residential services, except for very small settings with continuous staff presence, no economies of scale were evident. They observed that increased per-resident costs for staffing arise only when the staff ratio can no longer be held constant as resident numbers fall. When resident numbers are such that only *one* staff member at a time is required on duty, a further reduction of staff (below one) is not possible when continuous staffing is needed, so if resident numbers drop still further, staffing cannot be reduced proportionally and staffing ratios and per-resident staff costs usually rise (Felce & Emerson, in press; Felce et al., 2003; Stancliffe, in press). Such diseconomies of very small scale apply only in settings requiring continuous paid staffing. For settings that do not involve full-time staff (such as semi-independent living), staffing ratios (and costs) can be held constant as resident numbers fall (see Emerson et al., in press; Stancliffe, in press). Similarly, in support arrangements that do not involve 24-hour payment even if 24-hour support is provided – as in adult foster/host-family support, companion models, and supported living with some unpaid natural support – economies of small scale likely do not affect staff costs.

The available evidence suggests that economies of scale play little or no role in the cost of many community residential services and only have a significant influence in very small settings with continuous paid staffing. These findings, taken together with the trend toward more individualized

services and provision of individual budgets, indicate that substantially more individualized supports can be provided without necessarily increasing average per-person costs, but that this is unlikely to be accomplished exclusively through smaller and smaller residences with full-time staffing.

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## ■ Conclusion

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Growing demands for services and supports, in an economic climate that seeks to limit the growth of public expenditures, create increased pressure for accountability for both costs and outcomes in community supports. Increasingly, support systems will be explicitly challenged to increase cost-effectiveness (i.e., obtain better outcomes at lower or equal cost, or equal outcomes at lower cost). Although there is much left to learn in increasing cost-effectiveness, there is a promising foundation of research and experience to guide these efforts. The challenge will be to adopt these promising practices in systems that have, in the past, been slow to change.

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## ■ Additional Information

All stakeholders require up-to-date information on current ID/DD expenditures, enrollment patterns, trends, and Medicaid program variations. Greater detail on the topic of this *Policy Research Brief* may be found in *Costs and Outcomes of Community Services for People with Intellectual Disabilities*, by R.J. Stancliffe and K.C. Lakin, with a projected release date of September 2004, published by Paul H. Brookes Publishing. In addition, two other useful sources of expenditure data are the University of Minnesota and the University of Colorado:

- **University of Minnesota.** For several decades, the University of Minnesota's Research and Training Center on Community Living has gathered and reported national data that document and analyze status and trends in service use and expenditures for Medicaid HCBS and ICF/MR programs nationally and for individual states (e.g., Prouty et al., 2003). In addition, the center undertakes specific-purpose national surveys of important issues, such as waiting lists (Polister, 2002) and staff wages (Polister, Lakin, & Prouty, 2003). To access research findings, as well as other information from and about the center, visit its Web site at <http://rtc.umn.edu> or call 612/624-6328.
- **University of Colorado.** The University of Colorado's State of the States project collects data on the programmatic structure and financing of ID/DD services nationally and for each state (Braddock, 2002; Rizzolo et al., 2004). This project identifies emerging trends and issues, as well as undertaking more focused surveys such as Status and Trends in Family Support Services in the U.S. to provide comprehensive data on family support spending and numbers of families served in each state and the U.S. (Parish et al., 2003). For further information about the State of the States project, its data collection, and findings visit its Web site at <http://www.cusys.edu/ColemanInstitute/stateofthestates> or call 303/735-3096.

## ■ Related RTC/Institute Resources

The following are resources from the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. Publications may be found online at the Web address noted for each item, or in print through the Institute's Publications Office. For information and costs on print copies call 612/624-4512 or e-mail [publications@icimail.umn.edu](mailto:publications@icimail.umn.edu).

- ***Impact: Feature Issue on Consumer-Controlled Budgets.*** (June 2004). This issue of the quarterly publication *Impact* includes articles on the impact of self-determination on supports and services; individual budgeting, control, and support – what systems need to tell people; pointers for families and individuals who want to manage their own services; finding, keeping and training staff when individuals and families control the budget; individual and family success stories as well as program profiles from around the country; and resources for additional information. Available online at <http://ici.umn.edu/products/newsletters.html#various>.
- ***Service Use By and Needs of Adults with Functional Limitations or ID/DD in the NHIS-D: Differences by Age, Gender and Disability*** (issue in *DD Data Brief* series). (December 2003). This publication summarizes findings from the National Health Interview Survey on Disability conducted by the U.S. Bureau of the Census, National Center on Health Statistics in 1994 and 1995. It examines employment services and status, personal supports used and needed, professional and mental health services, previous long-term care services, transportation services, preventative health care, and waiting for services. It focuses specifically on how service use and needs vary by age, gender, and disability group. Available online at <http://rtc.umn.edu/nhis/pubs.html>.
- ***Characteristics of and Service Use By Persons with MR/DD Living in Their Own Homes or With Family Members*** (issue in *MR/DD Data Brief* series). (April 2001). This publication uses the data from the National Health Interview Survey Disability Supplement to describe people with MR/DD living in the community in terms of basic demographic characteristics, functional and other limitations, residential services history, medical services received, social activities, transportation used, and waiting list status, and compares people with and without MR/DD in regard to health status and service, functional limitations, major activity status, and school status. Available online at <http://rtc.umn.edu/nhis/pubs.html>.
- ***Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2003.*** (July 2004). A report providing statistics on persons with developmental disabilities in state, non-state, and Medicaid-funded residential programs in the U.S. for the fiscal year ending June 30, 2003. Available online at <http://rtc.umn.edu/risp/index.html>.
- ***Policies and Resources Related to Waiting Lists of Persons with Mental Retardation and Related Developmental Disabilities.*** (2002). A report detailing the findings of a national survey of state directors of developmental disabilities services conducted in 1998. The survey covered four areas: type and content of statewide waiting lists, state laws and regulations addressing waiting lists, policies and initiatives to reduce or eliminate waiting lists, and assistance and access to services for persons on waiting lists. Available online at <http://rtc.umn.edu/pub#reports>.
- ***Qualitymall.org*** (<http://qualitymall.org>). This Web site has compiled resources and information available from organizations nationwide related to delivery of person-centered supports. The section titled Systems Change Shop includes 14 resources on cost effectiveness of services, including information about expenditures on various types of services for people with developmental disabilities and the outcomes enjoyed by service users. Implications for systems change are often explored, and products focus on specific initiatives, as well as information at a state and national level.

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- **Health Status, Health Care Utilization Patterns, and Health Care Outcomes of Persons with Intellectual Disabilities: A Review of the Literature (2002)**
- **Family Support for Families of Persons with Developmental Disabilities in the U.S.: Status and Trends (2001)**

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