

**The MiChoice Program and *Eager, et al. v. Engler, et al.*:
Using *Olmstead* to Expand Home and Community Based Care in Michigan**
Presentation to the Governor's Task Force on Medicaid Long Term Care

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I. Introduction

Thank you for inviting us to speak about two important civil rights cases: the 1999 United States Supreme Court case, *Olmstead v. L.C.*, and the litigation we were privileged to pursue, *Eager, et al. v. Engler, et al.* The *Eager* case, filed in 2002, sought to reopen and expand participation in MiChoice, Michigan's home and community based waiver program, which was virtually closed to new admissions in the fall of 2001. The settlement order in this case was entered in February of this year. As you know, one element of the settlement was a requirement that the Governor create this very task force. Thus, we are especially pleased to be presenting here today.

We know RoAnne invited us to speak because she thought it was important that everyone on the task force understand the legal framework for the state's efforts to rebalance the long term care system. Some of you already have a sophisticated understanding of this. But there are two crucial points we need to ensure everyone understands:

1. First, providing services and supports to people with disabilities in the most integrated setting possible is not just a nice idea or one that is responsive to consumer demand. It's required by federal law and that law has been upheld by the United States Supreme Court. Michigan, like all other states, has significant legal obligations pursuant to that law, and it has been far slower to meet those obligations than many other states.
2. Second, while the *Eager* case resulted in the creation of the Task Force, the reopening of the MiChoice program to new applicants, and a number of other important steps toward rebalancing the long term care system, it is only a baby step toward a coordinated system of long term care that allows consumers real choice, quality, and dignity. Lawsuits have to be narrowly focussed and settlements are by their very nature compromises, so the settlement of this lawsuit merely starts the ball rolling.

It will be largely up to this Task Force, working hand in hand with the Administration and the legislature, to ensure that true reform is achieved.

II. The *Olmstead* Decision

When it enacted the Americans with Disabilities Act (ADA) in 1990, Congress found that the history of individuals with disabilities in this country was one of isolation and segregation and that, despite some improvements, this reality was a continuing, serious, and pervasive form of discrimination. 42 USC §12101(2)(5). In *Olmstead v. L.C.*, 527 U.S. 581 (1999), the United States Supreme Court considered the remedies the ADA provided for people with disabilities who were isolated and segregated in an institution and declared that unjustified isolation of individuals with disabilities is a form of discrimination. In so doing, the Court made what is arguably its most important civil rights decisions in decades.

The case began in 1995 when two women with mental retardation and psychiatric conditions -- L.C. and E.W. -- contacted the Atlanta Legal Aid Society to ask for help leaving the state institution in which they were confined. The treating professionals at the facility agreed that the two women could live successfully in the community if they had the necessary supports,

and that Georgia offered community programs that could meet their needs. Unfortunately, the women continued to languish in a state facility simply because the community programs had no available slots.

The plaintiffs argued that by failing to place them in a community program, the State of Georgia was violating “the integration mandate,” a regulation adopted by the United States Department of Justice to enforce the ADA. This regulation states:

A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. 28 C.F.R. §35.130(d).

Plaintiffs alleged that the state, as public entity, was providing services, programs, and activities such as habilitation services, medical treatment, therapy, etc. that could be offered in the community, a more integrated and appropriate setting. The District Court found for the plaintiffs and the decision was affirmed by the Eleventh Circuit Court of Appeals. The State then appealed to the U.S. Supreme Court.

In affirming the ruling of the lower courts that unjustified isolation of persons with disabilities in institutions is a form of discrimination, the Court took note of two factors. First, unjustified isolation perpetuates the notion that those affected are unworthy or incapable of participating in community life. Second, confinement in an institution diminishes everyday life activities such as family relations, social contacts, work options, economic independence, educational advancement and cultural enrichment. To obtain the supports they needed, people with disabilities were required to sacrifice the essential elements of a complete life.

By declaring the unjustified isolation of people with disabilities to be a form of discrimination and thus a violation of the ADA, the Supreme Court gave every person with a disability -- young and old alike -- a potential claim against a state that requires them to remain in a facility or to enter a facility to receive services which could be provided in the community. The decision was not a complete victory for advocates, however, because the Court noted that states could prevail if they demonstrated that moving a large number of individuals out of institutions and into the community would fundamentally alter the nature of the state’s programs. Unfortunately, the Supreme Court gave little guidance as to what would constitute a successful “fundamental alteration” defense. A plurality of the Court suggested that a state could establish a defense if it demonstrated that it had a comprehensive, effectively working plan for moving individuals into the community and a waiting list for community based services that was moving at a reasonable pace and not controlled by the state’s desires to keep its facilities fully populated.

An excellent source of additional information about the *Olmstead* decision can be found at www.bazelon.org.

III. The Response to *Olmstead*

In response to the *Olmstead* decision, an Executive Order was issued by the President in

early 2001. This Executive Order directed all federal agencies to swiftly implement the *Olmstead* decision. It also created the New Freedom Initiative and required all federal agencies to examine their programs, policies and services to determine how those activities could be improved to promote the integration of people with disabilities into community life. Those reports have been compiled and are available at: www.hhs.gov/newfreedom/final/.

Of particular interest to this Task Force is the report of the U.S. Department of Health and Human Services, found at: <http://www.hhs.gov/newfreedom/final/hhs.html>. That report attributes much of the overuse of institutions to the bias in the Medicaid system that favors institutional placement. The report details a number of measures that states could take to rebalance their Medicaid systems in ways that would promote community integration. HHS has issued, through its Center for Medicare and Medicaid Services, a number of letters to state Medicaid directors informing them of options and opportunities for rebalancing.

Beyond studies and reports, the federal government has also been active in enforcing the *Olmstead* decision. Just last month, the U.S. Department of Justice issued a findings letter in which it detailed its determination that the State of California is violating the civil rights of nursing home residents in a particular facility by impeding the right of those individuals to receive services in the most integrated setting possible. Specifically, the state was cited for contributing to unnecessary isolation by: (1) failing to ensure that residents are adequately and timely assessed for placement in non-institutional settings upon admission and regularly thereafter; (2) failing to adequately inform residents of home and community based options and alternatives; and (3) failing to provide sufficient meaningful community options to reasonably accommodate residents who need placements, along with the supports and services they need to live in those settings. The complete findings letter is located at: http://www.usdoj.gov/crt/split/documents/laguna_honda_findlet_aug3.pdf

To assess the progress states are making to implement the *Olmstead* decision, the National Conference of State Legislatures has twice surveyed the states and issued a report on efforts and innovative practices. Unfortunately, Michigan has not fared well in either report. For example, in the report issued in February 2004 for calendar year 2003, 29 states were identified as having an *Olmstead* plan or report. Michigan was not among them.

IV. The MiChoice Program

The Home and Community Based Waiver for the Elderly and Disabled is a nationwide program which has been administered by the Centers for Medicare and Medicaid Services (formerly HCFA) since the early 1980s. In 1992, when Michigan initiated the MiChoice pilot project in 11 counties, it was one of the last states in the country to take advantage of this federal initiative. The program gradually expanded until it became available statewide in 1998. In 2001, MiChoice served almost 15,000 individuals.

Under the program, individuals who qualify for Medicaid funded nursing home care may receive more than a dozen long term care services at home including personal care, homemaking, respite care, home delivered meals, chore services, and other assistance. The state enters into contracts with waiver agents, including all the state's Area Agencies on Aging and a

number of other nonprofit providers, to administer the program in 16 regions of the state. Waiver agents are responsible for screening and assessment of applicants, care planning, orchestrating the provision of services, data collection, and financial management of their programs. Although there was virtually no publicity about MiChoice, demand for the program consistently outstripped the supply of waiver slots and the program was full long before the end of each fiscal year.

On October, 1, 2001, then Governor Engler restricted funding to the waiver program, thus resulting in the closure of the program to virtually all new applicants and, ultimately, in a devastating reduction in the number of waiver clients served. Currently, we have fewer than two thirds the number of waiver participants we had in 2001. And that means in virtually all parts of the state, including where most of you live, if your neighbors or family member or friends seek waiver services to get out of or stay out of a nursing home, they will likely face long waiting lists.

V. *Eager v. Engler*

A. Background

In March, 2002, seven individual plaintiffs and five organizational plaintiffs filed *Eager, et al. v. Engler, et al.* to challenge the virtual closure of the MiChoice Program to new applicants. The claims in that case arose under the Medical Assistance Act, the Americans with Disabilities Act, and Section 504 of the Rehabilitation Act of 1973. We were privileged to represent the plaintiffs in that case.

The lawsuit alleged several violations of the Medicaid law and that the State was unlawfully and unnecessarily segregating people with disabilities in nursing homes rather than serving them in the most integrated setting appropriate to their needs -- their own homes. Plaintiffs requested declaratory and injunctive relief including an Order requiring the admission of the individual plaintiffs to the waiver program, reopening of the program, the creation of waiting lists for MiChoice, and the provision of information to the public about the MiChoice program.

B. The Individual Plaintiffs

The individual plaintiffs in the lawsuit represent the vast variety of Michigan citizens who need long term care. They ranged in age from 29 to 100, were African American and white, resided in nursing homes or were just barely surviving in the community, and lived in both urban and rural settings across the state. When we talk about long term care reform, in all its complexity, we sometimes forget the power and the poignancy of the lives of individual long term care consumers and the reason -- along with the state's budgetary constraints and the requirements of the law -- that it is so important that we create long term care options where people want to receive them -- in their own homes and communities. Thus, we want to take a minute to share with you the stories of some of our plaintiffs:

Robert Eager is a divorced, middle aged Traverse City resident with three children who

was diagnosed with Multiple Sclerosis that has progressed very rapidly. A former factory supervisor, Mr. Eager, is now challenged and exhausted by virtually every activity of daily living. Despite his very significant and progressive disability, Mr. Eager feared and dreaded nursing home placement because it would take him away from his children. Though normally a genial and optimistic person, Mr. Eager repeatedly stated that he would refuse food and water if forced to enter a nursing home. Because of the settlement of this lawsuit, Mr. Eager now receives a moderate number of waiver services which enable him to remain home with his children. Through sheer determination, courage, and the kindness of friends, Mr. Eager managed to remain in the community during the pendency of the lawsuit. When we told him the case had settled and he would finally get the waiver services he needed, he cried with joy and so did we.

☐ Terrell King is a 31 year old Detroit resident who resided in Madonna nursing home for many years. He was paralyzed from the neck down as the result of a football injury in 1992 and entered the nursing home after his mother was no longer able to care for him at home. Mr. King was desperate to leave the nursing home so that he could enjoy a social life and lifestyle more appropriate to his age and so that he could pursue an education. As a result of the settlement, Mr. King left the nursing home and regained his freedom.

☐ Georgette Kraft is an elderly woman who suffers from Alzheimers Disease. Her devoted husband of many years took care of her until his own declining health forced him to place her in a nursing home. Both Mr. and Mrs. Kraft wanted only to spend their last days together in their own home. Because of the settlement of the lawsuit, they will be able to do so.

☐ Howard Hugger was 100 years old when we filed the lawsuit. After living independently with waiver services, he had several falls and was ultimately forced to enter a nursing home. During his stay, he lost a substantial amount of weight, was dissatisfied with his care, became sluggish and depressed, and constantly asked his niece, a 61 year old woman with significant disabilities, to take him home with her. Mr. Hugger's niece did take him home where Mr. Hugger appeared content, congenial and active. Although Mr. Hugger's niece lived in a small, unassuming home, Mr. Hugger declared it his castle and stated repeatedly he wanted to spend the rest of his life there. However, because of his niece's own disabilities and the absence of waiver or other limited and inexpensive support services to help her bathe and care for Mr. Hugger, she was ultimately forced to take Mr. Hugger back to the nursing home not long after the suit was filed. He died there shortly thereafter. Mr. Hugger didn't have a happy ending to his long life, but if waiver services had been available to him in his niece's house, he would have.

C. The Settlement

We engaged in wide-ranging, detailed, thoughtful, and ultimately successful settlement negotiations with the Granholm Administration over a period of many months last year. The final Stipulation of Settlement was signed by Judge David McKeague of federal district court on February 2, 2004. The court will retain jurisdiction of the case during the implementation of the settlement.

The terms of the settlement provide both short term and longer term relief and serve as a stepping stone for future reform. Among the provisions of the settlement are:

- ❑ All surviving individual name plaintiffs have been admitted to the MiChoice program.
- ❑ During FY '03, approximately 1745 new participants were admitted to the MiChoice program.
- ❑ For FY '04, the state was required to allocate no less than \$100 million to the MiChoice program. However, with that limited allocation, the number of participants in the program will continue and has continued to decline. Therefore, the state also agreed to seek approval from the Centers for Medicare and Medicaid Services to convert certain state only expenditures to Medicaid benefits, thus drawing down federal matching funds in the amount of approximately \$25 million. We were very greatly disappointed to learn after the settlement of the case, however, that the state had discovered a technical obstacle to obtaining this money and that it will not now be forthcoming. Finally, the state agreed to make good faith efforts to obtain an additional \$25 million for the MiChoice program through reallocation of other long term care funding, but they have been unable to produce that funding. Thus, while we are pleased that limited admissions to the program have occurred as the result of the settlement, because funding for the program this year has remained stalled at \$100 million, far less than was spent on the program several years ago, we are still going backwards, instead of forwards, in providing home and community based services.
- ❑ DCH will make a number of efforts to ensure greater public understanding of long term care options, including the MiChoice program, by developing, distributing and posting public information and educational materials to consumers, families, providers, and other interested parties. These materials will be mailed to all current Medicaid recipients receiving long term care and all Medicaid enrolled providers. Thereafter, the materials will be provided to all applicants to FIA for Medicaid-funded long term care. In addition, long term care providers will be required to distribute materials to consumers applying for nursing facility or waiver services and both providers and consumers will be required to sign a form that the information was provided. Finally, DCH must organize an annual training for interested parties such as long term care ombudsman staff and hospital discharge planners to educate them about long term care options including the MiChoice program. These efforts will both increase public understanding of the limited home and community based options currently available and educate consumers and providers that nursing homes need not be the only stop on the long term care continuum. We are pleased to report that DCH staff are working diligently and energetically to meet these obligations and are working closely with us to ensure the consumer information is clear and effective.
- ❑ DCH will utilize identical functional/medical criteria for both applicants for the MiChoice program and applicants to nursing facilities. Applicants found ineligible for Medicaid funded long term care services will be given written notice of the

determination and an opportunity to appeal. The creation of identical functional and medical criteria for admission to the waiver program and nursing facilities will correct the historical practice that only a doctor's signature was required to be admitted to a nursing home -- making it easy to gain admission to the most expensive long term care option -- but a full screen was required before applicants were admitted to the waiver program, making it more difficult to be approved for waiver services. DCH has already circulated its draft screening criteria and sought public comment. We understand the state intends to begin using this new tool in the next few months.

- ❑ Waiver agents are also now required to maintain "contact logs" to document the number of applicants who request waiver services but for whom no services are currently available. Previously, waiver agents were instructed not to maintain such lists, making it much harder to track consumer demand for the program. The state is also seeking approval from CMS to require waiting lists and has published for public comment a proposed policy regarding how waiting lists are to be maintained and utilized. Under the proposal, waiver agents must give priority to certain categories of applicants, notify the state monthly of the number of people on the waiting list, and notify applicants monthly of their progress up the waiting list.
- ❑ DCH is also required to make a good faith effort to seek and use funding to help individuals transition from nursing facilities into available community-based settings. In the same proposed policy in which it described the waiting list requirements, DCH has included information about how requests for transition funding will be handled, and that policy is awaiting final promulgation.
- ❑ The final requirement in the settlement is the creation of this Task Force and the submission of an interim and final report by the Task Force. Although the Task Force began its work later than was anticipated in the settlement, we very much appreciate the significant effort members are making to ensure it fulfills its obligations.

VI. Conclusion and Recommendations

As we noted, these settlement elements, though significant, remain only a first step on the very long road to ensuring all long term care consumers receive high quality and adequate services and supports in the setting of their choice. It is a road many other states embarked upon long before we did. We think, however, that there are three important next steps that we urge the Task Force to consider and which are essential to continue the progress begun in *Eager*:

1. The elastic expansion of the capacity of the MiChoice program to meet consumer demand and eliminate waiting lists. We understand the federal government will approve the State's request for additional waiver slots and no rebalancing of the system is possible if these slots do not exist. The waiver agents' waiting lists, combined with analysis of demographic data and other resources, can help us determine with relative accuracy how many waiver slots are required to meet demand. Slot availability must be adjusted at least annually to respond to consumers' needs.

2. **Eliminate artificial funding caps for waiver services.** Currently, waiver agents are limited to an aggregate cap of \$42/day per client--less than half the cost of nursing home care -- despite the fact that federal law stipulates only that waiver services cannot, on average, *exceed* the cost of nursing home care. This artificial limitation prevents the waiver program from being a true alternative to nursing home care for many eligible consumers and, according to AARP's expert, Dann Milne, may be the lowest limit in the United States.

3. **Invest substantially in transition services for individuals who wish to leave the nursing home.** The long term care system cannot be rebalanced as long as beds are filled with people who do not need or want to be there. Advocates have documented that the average nursing home transition costs approximately \$3000 including such expenses as security deposits, transportation, purchase of household goods, home modifications, etc.-- less than the average cost of a month's nursing home stay. Some of the individuals who are able to relocate to the community then require only minimal services or services that cost far less than institutionalization. While the Department is proposing limited funding for transition costs, a much more substantial effort must be made to identify individuals who want to transition out of facilities and to develop and implement transition plans to help them do so. If we are truly committed to increasing community based services, we must pay the limited cost of permitting institutionalized consumers to access those services. Moreover, many of these transitions will reap long term savings for the state.

In closing, we want to acknowledge the determined efforts of the multitude of stakeholders and advocates who supported us during the litigation and continue to push for reforms. We also particularly appreciate the dedication of staff from the Michigan Department of Community Health who have worked hard to reach and implement the settlement. Instead of being adversarial during our negotiations and subsequent conversations, they have been consistently thoughtful, professional, compassionate, open and collegial. We are especially grateful to Paul Reinhart, Mary Gear, Deanna Mitchell, Steve Bachleda, Jan Christensen and Sharon Gire. In addition, we are delighted with RoAnne Chaney's and Susan Steinke's superb leadership on this Task Force and with the enormous commitment of the members of the Task Force. We look forward to working with all of you.