

A Brief History of Olmstead Activities in Iowa

Prepared for the Olmstead Consumer Task Force

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- June 22, 1999 - the United States Supreme Court issued the decision in *Olmstead, et al. v. L.C. and E.W.*, interpreting a provision of Title II of the Americans with Disabilities Act of 1990 (the ADA).

Under the ADA, states must administer their programs, services, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." This rule is the foundation for the *Olmstead* decision, which made it clear that the unnecessary segregation of individuals with disabilities is discrimination that violates the ADA.

Unnecessary segregation can occur when states administer programs in such a way that individuals with disabilities have no other option than to live in an institution in order to receive needed services and treatment. The *Olmstead* decision challenged states to review their current service delivery system and to develop comprehensive, effectively working plans to offer disability-related services in the most integrated setting appropriate to the needs of each qualified person.

- January 14, 2000 - The Centers for Medicare and Medicaid (CMS) issued a letter to all state Medicaid directors, calling upon them to develop comprehensive effectively working plans in response to the *Olmstead* decision, and made rule changes at the federal level to allow states more flexibility in planning. The letter said, in part, ". . . *no one should have to live in an institution or a nursing home if they can live in the community with the right support.*"
- June 18, 2001 - President George W. Bush issued Executive Order 13217, also known as the New Freedom Initiative, which called upon federal agencies to provide technical assistance to states, identify barriers, and pursue investigation and enforcement activities to support implementation of the decision.
- May 2000 - Governor Tom Vilsack named the Iowa Department of Human Services (DHS) as the lead agency in developing Iowa's response to the public policy issues raised by the *Olmstead* decision.
- August 2000 - DHS submitted a preliminary report to the Governor outlining the current state of the disabilities services system in Iowa, and hired an Olmstead Coordinator to gather public input.

- October 20, 2000 through January 19, 2001 - Twenty *Olmstead* Teamwork Meetings were held across the state to provide a forum for consumers, family members, and other interested individuals and groups to share their views. Over 400 people—a majority of whom were consumers or family members—attended the meetings, which were planned in partnership with Iowa's seven Centers for Independent Living and thirteen Area Agencies on Aging. Included in the meeting sites were both Woodward and Glenwood Resource Centers, and the Mental Health Institutes at Cherokee and Independence.

Five key areas guided the discussion:

- Health care and medical services
- Housing
- Transportation
- Employment
- Choice and community support

And three key questions were asked in each area:

- What is working?
- What is not working or not available?
- What are the barriers to community living?

- January 2001 - A statewide *Olmstead* Steering Committee was formed to begin development of a draft plan for Iowa based on the input gathered. The initial members of the committee were primarily *Olmstead* Teamwork Meeting participants.
- April 20 to May 20, 2001 - The Steering Committee's draft plan was made available for public comment. The committee re-organized as the *Olmstead* Oversight and Implementation Committee.
- July 1, 2001 - The Iowa Plan for Community Development was released, and Iowa's application for a federal Real Choices System Change Grant was submitted.
- 2002 - Iowa received funding for the Real Choices System Change Grant. The purpose of the project was to "Remove the institutional bias in Iowa's service system and afford Iowans with disabilities and Iowans who are elderly real choices about living in the community," with three central goals:
 1. Prevent institutionalization of people with mental retardation, developmental disabilities, mental illness, brain injury, or other disabilities and people who are elderly by developing a coordinated system of community supports and transition services that make life in the community possible for persons in Iowa.

2. Increase consumer choice in identifying and securing community supports and services for those who could live more successfully in the community with appropriate supports.
 3. Facilitate development of a broader range of services for persons with disabilities in Iowa and stronger linkages for information about those services.
- 2002 - Olmstead Committee membership was expanded and became the Olmstead Real Choices Consumer Task Force. Iowa also received federal funding through the:
 - Administration on Aging Seamless System Grant
 - Medicaid Infrastructure Grant
 - February 4, 2003 - Governor Tom Vilsack signed Executive Order 27, calling on state agencies to plan and move swiftly to implement the Olmstead decision in Iowa, and representatives from the state agencies were added to the Olmstead
 - March 27, 2003 - First Lt. Governor's Summit on Housing for Persons with Disabilities. In Governor Tom Vilsack's second inaugural speech he set a goal to invest in housing for people with disabilities in Iowa. This summit kicked off that effort, which resulted in the preservation or creation of more than 1000 units of accessible, affordable housing by August 2006.
 - 2003 - Iowa received funding for:
 - The Aging and Disability Resource Center
 - Smart Start Transition Project
 - Improving Transition Outcomes for Youth with Disabilities Grant
 - 2004 - State agencies completed self-assessment process and began to develop their agency plans to address Olmstead
 - 2004 - Iowa General Assembly called for a redesign of the disability services systems for adults and children in Iowa
 - 2004 - changes are developed for Medicaid Waivers to better support choice, flexibility, and self-determination, including a "cash and counseling" option
 - 2004 - Iowa received funding for the Family Support 360 Grant and continued funding for the State Mental Health Data Infrastructure Grant, which was first awarded in 2001

- August 24, 2007 - Iowa Olmstead Policy Summit on Cross-Cutting State Policy Issues Affecting Older Iowans and Iowans with Disabilities was held. The report of the summit formed the basis for the Olmstead Consumer Taskforce to identify four public policy priority areas supporting "community, opportunity, and prosperity" for all:

Priority One: PEER ADVOCACY TRAINING AND SUPPORT - Engage Iowans with disabilities to teach advocacy skills to other people with disabilities.

Priority Two: NEEDS-BASED REVISION OF ELIGIBILITY CRITERIA - Modify income and asset standards and base eligibility criteria on what an individual needs to maintain a dignified life.

Priority Three: FULL COMMUNITY INCLUSION - Assure full inclusion of Iowans with disabilities and older Iowans in all segments of their communities.

Priority Four: PROTECT ACCESS TO SERVICES WHILE SUPPORTING FINANCIAL INDEPENDENCE - Raise the state SSI Supplemental rates to a level that supports moving out of poverty, while preserving all other services and benefits including those provided at the county level.

- 2005-2009 and Beyond . . .

Also over the last five years, these projects, initiatives, and other system change activities too numerous to mention here have reflected the principles and priorities identified in the 2001 Iowa Plan for Community Development. Just a few notable examples of those efforts include:

- Ongoing mental health and disability services system redesign, lead by the Department of Human Services, with an emphasis on building community capacity, filling service gaps, and supporting choice.
- The Children's System Design initiative and the SAMHSA System of Care Grant, which emphasizes supporting children and families in their homes and communities, coordinating medical and social services, and using child-focused, family driven, and strength-based approaches to services.
- The Money Follows the Person Grant project, which incorporates the principle of money following the person from institutional settings into the community, and utilizes "Transition Specialists" who are carrying out functions analogous to those identified in 2001 for "Community Living Specialists."

- The Medicaid Consumer Choice Option, which offers self-directed personal care, employment, and community services and supports, as well as other Medicaid program changes that increase flexibility and personal choice.
- The Housing for Persons with Disabilities State Action Plan, which emphasizes universal design concepts and home ownership opportunities, and builds on the efforts begun by the Lt. Governor's Summit on Housing for People with Disabilities.
- The Iowa Finance Authority actively supports home ownership for low income Iowans and Iowans with disabilities through the federally subsidized Section 8 program and the federal "Home of Your Own" program.
- The IowaAble program provides loans to help make homes disability accessible and improve access.
- The Iowa Building Code, which applies in the absence of city or county codes, is now compliant with ADA Accessibility Guidelines for Buildings and Facilities.
- Expanded employment resources including the Social Security Administration's Plan for Achieving Self-Sufficiency (PASS) and Ticket to Work Program, Iowa Workforce Development's Disability Navigators, and increased awareness of the Medicaid for Employed Persons (MEPD) program.
- The Iowa Department of Economic Development and Iowa Workforce Development work more closely together to ensure that people with disabilities are hired through businesses receiving IDED funds and through targeted small business and Entrepreneurs with Disabilities programs.
- The State Resource Centers Barriers Report that lays out the specific barriers to community living that still exist for State Resource Center residents, based on surveys of residents, family members, and direct care staff.

It is exciting to note once again that this is only a representative sample of the systemic improvements that have occurred in Iowa since 1999, and while there is still a great deal of work to be done, the attention that the *Olmstead* Decision focused on ensuring choice and self-determination for people with disabilities planted the seeds for a wide array of systems change initiatives that have yielded benefits for Iowans with disabilities and older Iowans, and will continue to grow beyond the 10th anniversary of *Olmstead*.

Outline of the 2001 Iowa Plan for Community Development and Olmstead Steering Committee Recommendations for Systems Change

Following are the key steps, principles, and priorities identified through the Olmstead public meeting process and included in the July 1, 2001 Iowa Plan for Community Development:

INITIAL STEPS TOWARD SYSTEMS CHANGE

- Step One: Identify all stakeholders and their roles in the process
- Step Two: Identify people currently living in institutional settings (gather aggregate data)
- Step Three: Provide information and education including:
- Information on individual rights and informed choice
 - Information provided prior to admission to a facility
 - Information explaining appeal rights
- Step Four: Individually assess needs and preferences of individuals living in institutional settings
- Step Five: Identify and train community living specialists
- Step Six: Develop and provide coordinated transition services
- Step Seven: Establish a coordinated transition process and pursue community integration activities
- Step Eight: Development and maintain a comprehensive and accurate waiting list for community services
Identify specific barriers and use the information to address barriers and fill gaps in services
- System-Wide Coordination: Build greater continuity among state, county, and municipal activities

RECOMMENDATIONS FOR SYSTEMS CHANGE

Health Care and Medical Services Priorities

- Fund people
- Overcome institutional bias
- Ease asset and income restrictions
- Engage in systemic staff development activities
- Implement a personal assistance program
- Adopt Medicaid personal care option
- Assure availability of Medicaid providers
- Support affordable health insurance

- Make maximum use of federal funds
- Adopt federal Medicaid policy changes
- Extend 300% [of poverty] eligibility benefit [to eligible people before they enter a nursing home]
- Educate physicians and medical professionals
- Improve EPSDT access for children
- Provide for children's mental health treatment
- Plan for change
- Transition facilities as well as people
- Increase integration opportunities
- Prevent fraud and abuse

Housing Priorities

- Expand funding for home modification
- Seek federal funding
- Enforce existing accessibility standards and building codes
- Foster community development
- Ease income and asset restrictions
- Support home ownership
- Examine market rental costs
- Create a clearinghouse for housing information
- Share equipment
- Expand assisted living
- Coordinate accessibility resources
- Encourage community trusts

Transportation Priorities

- Add transportation as a Medicaid service
- Utilize transportation vouchers
- Remove regulatory barriers
- Expand service hours
- Develop public/private partnerships
- Encourage cooperative efforts
- Increase vehicle modification funding

Employment Priorities

- Emphasize the importance of employment
- Acknowledge abilities
- Ease income & asset restrictions

- Bridge transportation barriers
- Allow personal assistance services at work
- Expand job choice
- Encourage job advancement
- Provide introduction to work programs when needed
- Expand job coaching and support
- Strengthen interagency cooperation
- Support community development
- Coordinate employer mentoring
- Emphasize quality in education
- Offer educational grants
- Show leadership:
 - Actively involve workforce development in job development and marketing for people with disabilities.
 - Show state leadership in hiring people with disabilities

CHOICE AND COMMUNITY SUPPORT PRIORITIES

- Coordinate community staff development
- Fund people
- Designate special funding for intensive needs
- Develop and implement crisis services
- Support children at risk of out of home placement
- Establish a coordinated system of transition services
- Develop specialized behavioral services
- Make community living specialists available
- Develop a statewide standard of core services
- Simplify HCBS Waivers
- Increase flexibility of Waivers by basing eligibility criteria on needs, not diagnosis
- Assure appeal rights
- Foster independence
- Encourage natural supports
- Protect payee independence
- Consider vouchers
- Provide conflict resolution
- Encourage home-based respite
- Provide clear, accurate information
- Initiate community development

OLMSTEAD REAL CHOICES TASK FORCE MISSION STATEMENT (2001)

The human condition is enriched by our natural diversity. Individuals with disabilities must not be unnecessarily segregated from the mainstream of society. They must have opportunities to live fully integrated lives in the communities of their choosing.

How individuals live and have the opportunity to make personal choices in any type of setting is equally as important as where they live. Individuals who choose to live in traditionally "institutional" facilities still need significant integration opportunities and can be afforded a wide range of personal choices in their daily lives. Individuals who choose to live in "community" settings still remain isolated and segregated from the mainstream of community life if they do not have access to the services and supports they need to be an active part of their community and be involved with other members of the community.

The choice of appropriate living arrangement and level of integration desired must be based on the informed and educated decision of the individual, with the advice and support of his or her guardian, advocates, and personal support network. The overriding goal of an integrated services system must be to present each consumer with a full range of appropriate options for service delivery and to assure that each consumer's individual rights and personal preference are respected and supported in the setting that person chooses.

IOWA PLAN FOR COMMUNITY DEVELOPMENT PRINCIPLES

The Iowa Plan for Community Development is a living document created to guide systems change activities for disability-related services in Iowa, taking into account the needs of all Iowans with disabilities. The Plan's governing principles are:

- **EFFECTIVELY WORKING PLAN.** To develop and implement a comprehensive, effectively working plan for providing services to eligible individuals with disabilities in more integrated, community-based settings.
- **CONSUMER AND FAMILY INVOLVEMENT.** To provide an opportunity for interested persons, including individuals with disabilities and their representatives, to be integral participants in plan development and follow-up.
- **NO UNJUSTIFIED INSTITUTIONALIZATION.** To take steps to prevent or correct current and future unjustified institutionalization of individuals with disabilities.
- **SUPPORT COMMUNITY LIVING.** To ensure that services are sufficient to meet the needs of persons with disabilities to live in their communities.

- **INFORMED CHOICE.** To afford individuals with disabilities and their families the opportunity to make informed choices regarding how their needs can best be met in community or institutional settings.
- **QUALITY STANDARDS.** To take steps to ensure that quality assurance, quality improvement and sound management support implementation of the plan.
- **STATEWIDE CONTINUUM.** To assure that a continuum of community integrated services are made available statewide.
- **MONEY FOLLOWS THE PERSON.** To afford individuals with disabilities and their families the opportunity to determine how public funding can best be used to meet their needs in community or institutional settings by allowing funds to follow the person.
- **NO DISCRIMINATION BASED ON SEVERITY OF NEED.** To assure that individuals are not discriminated against because of the severity of their disability or the complexity of their needs.
- **SUPPORT INDEPENDENCE.** To take steps to ensure that home health services are designed to support independence.
- **COMPREHENSIVE PERSONAL ATTENDANT SERVICES.** To take steps to expand and support the use of para-professionals to provide comprehensive personal attendant services.

~ Olmstead Real Choices Task Force
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