

ENSURING INFORMED CHOICE FOR INSTITUTIONALIZED INDIVIDUALS TO RECEIVE SERVICES IN THE MOST INTEGRATED SETTING

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Overview

- ADA principles and strategies to ensure informed choice for institutionalized persons
- Litigating informed choice
- Proving informed choice
- Providing informed choice by offering community services
- Providing informed choice by providing community services
- Lessons learned

The New Olmstead Challenge

- In a number of recent cases, and often as a result of last minute Olmstead Plans created after the filing of litigation, states have argued that they have fulfilled their obligation under Olmstead by offering institutionalized individuals an option to leave the facility
 - If the individual does not immediately accept the offer, the state concludes the person has made a choice not to leave the facility
- Similarly, courts have refused to certify classes, decertified classes, demanded class definitions that exclude persons who oppose, and allowed intervention by guardians who oppose community placement

The Impact of Disability on Decision Making

- The impact of cognitive, psychiatric, and other disabilities
 - Limitations in understanding, considering, and communicating options
 - Limitations in perception, reasoning, and conceptualizing of options
 - Desire to please
 - Fear of the unknown
- Environmental Factors and the Vestiges of institutionalization
 - Passivity and learned helplessness
 - Limited opportunities to make choices
 - Limited experiences of community options

Supports to Promote Informed Choice

- Assessment of capacity
- Information and education to support choice making
 - Decision making tools
 - Accessible information
 - Individualized modifications to choice making process
- Expanded opportunities to make choices
- Actual experience of community options

Reasonable Accommodations to Enable Informed Choice

- A public entity has a duty to provide reasonable accommodations that would allow the individual to meaningfully participate in its program
- This obligation extends to the choice of whether to remain or leave an institution
- The obligation requires the entity to provide whatever supports, information, education, opportunities, and experiences are necessary to accommodate the impact of the disability on the individual's ability to make an informed choice of whether to oppose community living

Accommodations to the Impact of Disability on Informed Choice

- Accessible, available, and individually- appropriate community supports that fully address the person's needs and preferences
- Individualized transition process that describes the person's preferences and needs and begins with the presumption that the person can live in the community
- Identification of concrete alternatives that address preferences and needs, and that are incorporated in transition plan

Accommodations to the Impact of Disability on Informed Choice (2)

- Periodic and accessible information about community living
- Practical and ongoing opportunities to experience community living
- Support services that allow the person to participate in community activities while still in the facility
- Qualified professional to assist in the transition planning and process

Accommodations to the Impact of Institutionalization on Informed Choice

- There is a separate and distinct obligation to redress the vestiges of unnecessary institutionalization and its impact on decision making
 - The entity must accommodate the cause and consequences of unnecessary institutionalization
 - The entity must accommodate the vestiges of institutionalization with opportunities to experience the community
- The absence of a request to transition is not an informed choice to remain in the facility
 - The entity must offer concrete and feasible alternatives that reflect the person's preferences and needs

Litigating the Issue of Choice: Defining the Class

- Decisions about choice need to be considered and addressed in formulating an Olmstead case
- Options to consider for the class definition:
 - All persons in the facility
 - All persons who have not made an informed decision to remain in the facility
 - All persons who have not objected to transition
 - All persons who have indicated an interest in leaving the facility, after receiving sufficient information that would allow an informed choice
 - All persons who have requested to leave the facility
- In Ohio, after extensive litigation and intervenor opposition, the court adopted a blend of option 4 & 5

Litigating the Issue of Choice: Defining the Remedy

- In order to determine who should receive community services, the remedy should specify the elements of an informed choice process, including:
 - A Peer-to-Peer in-reach program
 - A Family to Family program
 - Opportunities to see, visit and experience community programs
 - Videos that depict a range of community options and that include testimony from individuals and families who left ICFs to live in the HCBW system
 - Written materials that are at a minimum neutral and fair
 - The opportunity for the individual to express a choice, with supports as needed
 - A recognition that individuals may change their mind and that that this is reflected in repeated invitations to consider other options
- The Ohio settlement included some of these elements

Proving the Issue of Choice: The State's Evidence

- In response to litigation, Texas revised its nursing facility PASRR program, assigned case managers to each person with IDD in a nursing facility, and dedicated HCS waiver slots to diversion and transition
- Case managers provided written information semi-annually and recorded the person's choice about whether to stay or leave the nursing facility
- Case managers met monthly with the person to discuss needs and preferences
- Persons who chose to leave the facility had to complete a waiver application
- Approximately ½ of available waiver transition slots were used

Proving the Issue of Choice: The Plaintiffs' Evidence

- Experts reviewed a sample of individuals
 - Discussed community options, barriers, and preferences
 - Determined if the person was interested in exploring transition
 - Determined if the person had made an informed choice to remain
 - Aggregate data found that over 85% of sample had not made an informed choice to remain
- Research expert presented research and literature on challenges to making informed choices for persons with IDD or institutionalized persons, and what accommodations were necessary to ensure an informed choice
- Data analysts reviewed Medicaid billing data for case manager visits and concluded that half were less than 12 minutes

Providing Choice by Offering Community Services

- Hutchinson v. Patrick: Olmstead case on behalf of over 3,000 individuals with ABI in nursing facilities
- Settlement required the State to offer community services through two new waiver programs
- Included general obligation to create an education and information program for residents and family members
- Put burden on individual to request placement and apply for waiver

Providing Choice by Offering Community Services (2)

- Reliance on self-identification, facility staff or routine resident assessments/MDS data
- Limited use of third parties for outreach and informing function
- Reliance on large presentations/groups to communicate about integrated options
- Offered a brochure versus an experience
- Absence on ongoing engagement; solution-focused process
- Soon became clear different strategies to ensure informed choice were necessary due to numerous deficiencies in the choice and service request process

Providing Choice by Offering Community Services (3)

- Hutchinson 2.0 -- Repeated, in-person meetings
- Individualized information about options
- Agency staff experienced in community service provision conduct in-reach visits monthly to encourage persons to apply
- Process for addressing perceived barriers to community living
- Multi-media education strategies, videos
- Connecting with peers/family who transitioned
- Using state/waiver transition funds to provide opportunities for community exploration
- State directives to facilities re: support for in-reach access, records and referrals

Providing Choice by Providing Community Services

- Rolland v. Cellucci: Olmstead case on behalf of 1650 persons with IDD in nursing facilities
- First settlement required the State to transition 1100 individuals in nursing facilities to integrated settings
- Case managers were assigned to each individual, offered each a community placement, and provided some opportunities to leave the facility (specialized services)
 - Many (800) people chose the community – 400 immediately and 400 over time
 - But soon the number wanting to leave plateaued
 - The State starting focusing on new admissions since they were more interested in leaving

Providing Choice by Providing Community Services (2)

- A second settlement required the State to transition an additional 700 individuals and to create an informed choice process
- Discharge plans were developed for all residents that determined the nature, level, and location of supports needed to live safely in the community
- Intensive in-reach activities, including regular opportunities to engage with community programs, providers, and activities were developed
- Family to family and peer to peer programs were created to provide family members and residents information about successes from their peers

Providing Choice by Providing Community Services (3)

- Intensive medical and nursing supports were developed that dramatically expanded opportunities for persons with complex medical needs to live successfully in the community
- Outcome: almost all nursing facility residents (approximately 1800 of 2,000) moved to the community, including persons who had been in nursing facilities for many years, persons with intensive nursing needs, and persons who consistently opposed (or whose guardian consistently opposed) community living

Lessons Learned: Strategies to Use and Avoid

- Provide in person, individualized information
 - Avoid general group outreach sessions
- Engage in exploration and discovery process
 - Discuss goals, vision, priorities & specific alternatives
- Provide meaningful options that allow informed choice
 - Avoid asking for final decisions about transition before exhausting all options

Lessons Learned:

Strategies to Use and Avoid (2)

- Provide experiences and opportunities to engage in community activities
 - Avoid relying on written information or brochures
- Develop a transition plan for everyone that describes in detail what community living would look like
 - Avoid waiting for the person to assent to transition before developing a plan
- Determine what is necessary to support a successful transition
 - Acknowledge and work to address concerns/ barriers

Informed Choice by Persons Who Lack Capacity

- The role of guardians and families are determined through formal and informal procedures
- The UGCOPPA imposes limitations on the authority of guardians
- Effectuating the person's preferences through the substituted judgment standard
 - The role of courts in applying the standard
- Alternatives to guardianship
 - Supported decision making
- The default of community living

Supported Decision-Making

- Article 12 of the CRPD recognizes the right and ability of all persons to make decisions and to express their preferences, with appropriate supports
- Supported Decision-Making – drawing on a group of supporters the person chooses to help advise him/her about certain decision-making areas.
- Supporters can help the person obtain the necessary information and experiences that would allow them to make an informed choice, considering the pros and cons associated with a decision about where to live