

OLMSTEAD AND COMMUNITY

Implementing the New Freedom Initiative

Participant Workbook

**Produced by: Independent Living Research Utilization at TIRR
BIA, Inc.
Utah State University Center for Persons with Disabilities**

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The curriculum for this video-based course was developed, under the direction of ILRU, at the Utah State University Center for Persons with Disabilities. Dr. Judith Holt led the development team. She was assisted by Carri George, B.A. and Catherine E. Chambless, Ph.D.

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Introduction

Welcome Fellow Advocate...

In March 1998, Justin Dart said: “I propose that we of the disability community lead the revolution of empowerment... [this] is not empty rhetoric. There is a distinct and vital difference between society/government that empowers people, and a society/government that provides for them and regulates them for their own good...empowerment is when government joins with business, labor, religion, and individual citizens to guarantee every person the tool to govern, to produce and [to] live the best life possible for self and for all...we have unique knowledge and experience to offer. We have the responsibility to lead.”

It is more important now, than it ever has been, to become an effective advocate. There are thousands of our friends with disabilities who are living in institutions or nursing homes. There are even more who are living in the community but will need advocacy and support from us to remain in the community. It isn't easy to be an advocate, but it is necessary!

The Supreme Court decision known as *Olmstead vs. L.C.*, has changed the landscape for advocates. It provides the framework for advocacy to support persons with disabilities to transition out of nursing homes and other institutions into the community. *Olmstead* also supports persons with disabilities to remain in the community and not be placed in institutions.

Advocating can be a major challenge and yet a most rewarding experience. Advocating for a cause promotes reformation, a new perspective, and most of all greatness because advocating means stepping outside of comfort zones. It means doing something that the average person would not do...and it means opening up new worlds and new perspectives for yourself and for others. It is informing and—teaching.

The purpose of this course is to help you understand and apply the principles and the resources that successful advocates have used—to help you advocate for yourself and others.

A team of experienced advocates have come together to not only bring their own advocacy experiences to these lessons, but to gather the best principles from the most successful and experienced advocates for persons with disabilities. They did this in hopes of making your advocating more effective. They know what it's like to get the runaround and hit roadblocks, and experience the frustration. They also know how it feels when you are successful in getting people out of institutions as well as ensuring that people with disabilities live in communities.

The modules are full of information that will help you if you truly study and complete the exercises. Some of the modules have lists of resources after them which will be very helpful in finding more information. For some of you

(because you have had more experience) this information may be easy to understand...and for others it may be a little more difficult to understand because of the complexity. Be patient and continue to study. It will come.

The most helpful part will be if you already have an advocacy goal in mind when you begin the course. Helping people live in the community is always an excellent goal and requires advocacy in many different arenas. Having a goal will help the modules become meaningful and you can apply them to your current position. It will help you to take action when you receive the right information.

Good luck, and as Justin said, "...we have unique knowledge and experience to offer. We have the responsibility to lead."

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*It should be noted that there are two versions of Module 2 and Module 4. Module 2-IL and Module 4-IL contain information relevant to Independent Living staff and advocates, while Module 2-Transition and Module 4-Transition contain information that may be more relevant to transition age students and their families.

Olmstead and Community

Module 1: Disability Policy Framework

Workbook

Introduction

Read the quote below by Justin Dart, a prominent leader of the international disability rights movement:

“I, Justin Dart, am the starting place and hold complete responsibility for my revolution in my universe. It will be created by me, or it will not be. But what can I – one lonely individual – what can I do to make a difference?”

“I can’t run the government. I am society. I am the government. Only when I change, will society and the government change. Each one of us is responsible. Each one of us must lead and each one of us must recruit new leaders. If I can be a soldier of empowerment, so can you. You have the power. You are one unit of society, just like Nelson Mandela.”

“Get into politics as if your lives depend on it. And it does. You can be a soldier of justice. You can be a revolution of one. Let us unite in action, each in our own way. We have a dream. Join us in a society where everyone wins.”

Application and Discussion

What does this quote mean to you? How does it affect you?

Why do you want to learn about advocacy?

What is your purpose or goal to help someone? Write it down.

Writing your goal will help remind you of the reason you are learning about advocacy, and will help you understand how to apply critical principles in these lessons as you strive to reach your goal.

Sample goals:

- Assist “Joe” in obtaining transportation in the community to go to work.
- Help “Jane” in her efforts to be integrated into the regular education classrooms at the local high school.
- Find the services necessary to make it possible for “Russ” to leave a nursing home and live in the community.

Term Definitions

- **policy:** A set of laws and/or rules that are established by an authoritative body.
- **public policy:** A set of laws and rules made by a lawmaking body or a government agency.
- **inexpedient:** Not suitable or advisable. *Meteor Dictionary – dictionary.meteor.com/wnet/5088678.htm*
- **core precept says:** 1. Disability is a natural part of the human experience. 2. The approach is to fix the environment; not the individual.
- **methods of administration:** How laws are implemented or carried out to be consistent with their stated principles.

Objectives

Throughout this module you will watch portions of a video of Bobby Silverstein explaining critical concepts and strategies you need to understand in order to be an effective advocate. Between the sections of video you will complete exercises that will assist you to learn these concepts and strategies. Here are the important concepts you will be learning:

- Understand the history of institutionalization of people with disabilities in your state and community.
- Determine how the “old paradigm” of beliefs about people with disabilities affected policies in the past to understand how the beliefs need to be changed for the future.
- Learn about the “core precept” and four goals of the “new paradigm” of disability policy.
- Know how to ask questions about the institutions and laws to see if their principles meet the standards of the core precept and goals and apply this knowledge to your own advocacy plan.

Before you begin the module, read Robert Silverstein’s biography.

Biography

Robert Silverstein, J.D.
Director of CSADP

Robert “Bobby” Silverstein, J.D., is the Director of the Center for the Study and Advancement of Disability Policy (CSADP). Mr. Silverstein has over 25 years experience providing policy analysis and research for and technical assistance to policymakers. He has negotiated and drafted public policy at the federal, state, and local levels.

In his capacity, Mr. Silverstein played a central role in all important disability policy legislation produced between 1987-1997, including the landmark Americans with Disabilities Act, 15 other pieces of legislation, and numerous disability-related amendments to other bills concerning health, civil rights, education, and job training.

Silverstein has won respect from Republicans as well as Democrats, leaders of the disability community, representatives from state and local governments, and the business community for his commitment to developing bipartisan consensus legislation that is based on sound research.

History and Old Paradigm of Disability Policy

In this portion of the video, Bobby focuses on:

- A common set of principles, derived from sound policies, to use as a framework for advocating.
- The historical perspectives of policies and the importance of understanding them in order to make changes for the future.
- The old paradigm of disability policy and some examples.

Play the video, Module 1, Section 1: “Goals of Disability Policy” (8 minutes). After the section, stop the video and move on to the exercises below.

Application and Discussion

Bobby talked about the history of some institutions that were developed because of the work of commissions made up of policymakers and professionals. For example, one commission was called “Commission to Address Feeble-mindedness and the Menace of Feeble-mindedness.”

1. Name an example of an institution for people with disabilities in your state. Do you know the history? Who originally advocated for starting it?
2. What groups or individuals are advocating for maintaining the institution(s) in your state today? What about parent groups? Employees of institutions? Why do they support keeping the institutions open?
3. Do you know the opinions of agency officials or lawmakers about maintaining institutions? Who are the officials and what are their opinions?

Wisconsin Supreme Court Decision

"Merritt has been a crippled and defective child since his birth. Afflicted with a form of paralysis, which affects his whole physical and nervous makeup, he has not the normal control of his voice, hand, feet, and body. By reasons of said paralysis, his vocal chords are afflicted."

The School Board claimed that his physical condition and ailment produces a "depressing and nauseating effect on the teachers and school children; that by reason of his physical condition he takes up an undue portion of the teacher's time and attention, distracts the attention of other pupils, and interferes generally with the discipline and progress of the school."

The Wisconsin Supreme Court concluded that this child must be/may be excluded from public education because, "his presence is harmful to the best interests of the school. Individual rights must be subordinated to the general welfare."

4. Bobby used this example from Wisconsin to demonstrate some of the old paradigms for making policies.
 - Can you see evidence of the "old paradigm" in state programs or policies?
 - Are nursing homes the same as institutions?
5. Is there a particular person in an institution, nursing home, or the community that you plan to advocate for? Are there some barriers in the community that you would like to remove? If so, what are they? Write down your specific advocacy goal (your goal may become more specific as you advance through the modules).

New Paradigm of Disability Policy

In this section of the video, Bobby will discuss:

- The two main ideas in the core precept of the Disability Policy, which are:
 - Disability is a natural part of the human experience.
 - The approach is to fix the environment, not the individual.
- The need to communicate the core precept to the policymakers.
- The four goals of Disability Policy, which are:
 1. Equality of Opportunity.
 2. Full Participation.
 3. Independent Living.
 4. Economic Self-Sufficiency.
- Detail of Goal One: Equality of Opportunity.

Play the video, Module 1, Section 2: “The Core Precept and Goal Number One: Equality of Opportunity” (7 minutes). After Bobby finishes Goal One: Equality of Opportunity, proceed to the exercises.

Application and Discussion

The Core Precept

1. Look at the scenarios below and remember the two main ideas in the core precept that Bobby talked about:
 - Disability is a natural part of the human experience.
 - The approach is to fix the environment, not the individual.

Discuss how these two concepts apply to these scenarios.

Scenario: Jaylee, age 10, received brain damage at birth in a difficult delivery. Her ability to act quickly is impaired. At a birthday party, she is able to break the piñata, but before she can get any candy, all of the candy is gone.

Scenario: Bryan, age 15 and a talented basketball player, fell from a horse and suffered serious spinal cord damage. He lacks use of both legs. He still wants to play basketball.

Scenario: Mario likes to eat at a restaurant downtown, but he cannot access the building easily because the curb is not cut to allow wheelchair access.

2. Do you have an example of how society can “fix the environment” to provide effective and meaningful opportunities for people with disabilities? Explain.
3. Who would you contact to help implement this change? What will you need to communicate to this person to make it happen?

Goal One: Equality of Opportunity

1. Bobby mentions three components of Equality of Opportunity. Can you name the three components?

Individualization

2. Read these scenarios and answer the following questions.

Scenario: Petra is a 12 year old student with above average grades in school. She has cerebral palsy which makes her speech difficult for many people to understand. The school has provided her with a speech board to help with communication. She receives her education in a regular classroom.

Scenario: Arnold is a 24 year old man with Down Syndrome who wants a job. The local employment support agency interviews Arnold and his family and learns that he loves animals. The job coach develops a position for Arnold at a pet boarding kennel as a dog walker.

These are both examples of individualization. Can you identify some reasons why?

3. In terms of individualization, in what ways can programs base decisions on “facts and objective evidence” rather than on “stereotypes, prejudice, or fear?”

Effective and Meaningful Opportunity to Participate

“Nothing is more important” than effective, meaningful opportunity to participate. ~Bobby Silverstein

4. Scenario: A mother approaches her child’s teacher about letting her child, Amy, go to the lunchroom ahead of time to get her food because she has a difficult time chewing and swallowing her lunch in the time allotted for the lunch period. Amy has hypotonic (soft or weak) muscles in her throat and mouth, and is frustrated because she cannot finish her lunch in time to play with the other children after lunch, or she is late to class. In the conversation with the teacher, the mother mentions that her child should have “reasonable accommodation.” What should the classroom teacher do?
5. Scenario: Joe is 24, has a visual impairment, and can read any written materials that are in large print. He has recently completed certification as a medical coder and is seeking work in the health field. Joe says that all he needs is a screen reader device to enlarge computer screens or written materials. Is Joe asking for “special treatment”?

Inclusion and Integration

6. The last component of “Equality and Opportunity” that Bobby talked about is Inclusion and Integration or a person should be included, not segregated in order to get a public benefit. Have you ever experienced a time when you or someone you know with a disability has been segregated or isolated from others in order to receive a benefit? Is isolation ever justifiable? Explain.

Goal Two: Full Participation, Goal Three: Independent Living, and Goal Four: Economic Self-Sufficiency

In this section of the lesson, Bobby will discuss Goal Two: Full Participation, Goal Three: Independent Living, and Goal Four: Economic Self-Sufficiency.

When you finish the video, you will read about examples of each of these goals. Questions will also be provided to help you better understand the goals of Independent Living and Economic Self-Sufficiency.

Play the video, Module 1, Section 3: “Goal Two: Full Participation, Goal Three: Independent Living, and Goal Four: Economic Self-Sufficiency” (8 minutes). When Bobby finishes the section of goals Two, Three, and Four, stop the video and proceed to the exercises below.

Application and Discussion

Goal Two: Full Participation

Bobby talked about “Individual” and “Systems” components in Goal Two: Full Participation. Read the examples below of each component and answer the questions.

Individual

Scenario: Emily is a 14 year old student in special education. When Emily’s parents went to school for her IEP meeting, the teacher proposed that Emily be included in the meetings so that she would be able to contribute and feel a part of her own plan.

1. Look at the policies of schools, institutions, nursing homes, or other agencies and determine how people with disabilities are involved with decisions that affect their lives. Can you think of examples?
2. Why do you think it’s important for individuals to be involved directly in making decisions that affect their services and supports?
3. What does it mean to you to be “empowered, self-determined, self-advocating, and having informed choice?”
4. Should individuals with disabilities and/or their families be involved in decisions at the *individual person* level? Is this happening?

Systems

Scenario: John is an adult with HIV/AIDS. He was invited to be a member of the Medical Care Advisory Committee for the Department of Health.

5. What opportunities exist for individuals with disabilities and/or family members to be involved in decision-making at the *policy* level? What type of policies can be influenced?

Goal Three: Independent Living

Read the story of Monica, who is transitioning to independent living; then answer the questions.

Scenario: Monica is 28 and qualifies for living support services because of her disability. She has always lived with her parents until they passed away recently. The support agency is helping Monica to find an apartment and a job near where she has siblings and friends.

1. Discuss how programs support independent living. What supports are available and what supports are missing in your communities?
2. Bobby says that under the new paradigm, independent living is considered a legitimate outcome of public policy. Do you think some policymakers regard independent living as *illegitimate*? Can you think of why people feel this way?
3. What does Bobby mean when he says that the policy should have provisions to support independent living skills and support for personal assistance services, assistive technology, and cash assistance?

Goal Four: Economic Self-Sufficiency

Read the example below of Economic Self-Sufficiency and answer the following questions.

Scenario: James Todd has a spinal cord injury (quadriplegia) due to a car accident at age 16. He is now 32, married with one daughter, and works as a computer technician for county government. His employer provides health insurance and retirement benefits so that he felt secure enough, a couple of years ago, to go off his Social Security Disability benefits. James said he did not want to live in poverty all his life.

1. Name some examples of supports that were in place for James Todd to be able to achieve this level of self-sufficiency. Are the services available for you locally?
2. Are you aware of any new policy changes in your state that support people with disabilities to work? What are they?

The “Checklist,” Methods of Administration, and Advocacy Plan

In this section we will discuss a checklist that helps to determine if important components of a policy are present. We will also discuss how to address the methods of administration for your advocacy plan. Then we will take you through the steps of developing an advocacy plan by using a simple planning model.

Disability Policy Framework	Checklist: The questions to ask ourselves
A. History	Do we know the history?
B. Core Precept 1. Disability natural part of human experience. 2. Fix environment, not individual.	Are we addressing the core precept in our change efforts?
C. Four Goals of D.P. 1. Equality of Opportunity.	Are the decisions based on the individual? Does the plan provide meaningful opportunity for all? Do people need to be segregated to receive public benefit?
2. Full Participation.	How are people w/disabilities involved w/decisions that affect their lives? How are people w/disabilities involved at the policy level?
3. Independent Living.	Does the system support independent living?
4. Economic Self-Sufficiency.	Does the system support work? Are there work incentives?
D. General Administration	Does the plan respond to people's needs?

Table 1. Table of checklist questions to ask ourselves when looking at a policy to see which components of the Disability Framework are in place and which are missing.

Checklist

Throughout the video Bobby refers to a very important “Checklist.” The Checklist consists of questions we should ask about the policy we are working with, and *helps us know if the policy reflects the values and approaches of the new paradigm*. These questions ask:

- Is a certain component present?
- Are certain activities happening?

When these questions are compiled all together, the answers to the checklist questions can tell us which components of the “Disability Policy Framework” are in place and which ones are missing.

Examine Table 1 and notice each of the questions pertaining to the sections Bobby talked about. These questions are key as you look at policies you are interested in to determine if all of the components are in place.

Methods of Administration

In this module you have learned, according to Bobby, “only half” of what you need to know in order to advocate effectively for people with disabilities. Why does he say that? Because while the history, core precept, and four goals are important, what we really care about is implementation—if the policies are working or making a positive difference in the community. Bobby calls this other part “methods of administration.”

Did the principles really guide behavior? Paying attention to the methods of administration means that you need to find out if the programs or rules are responding to the needs of people with disabilities or are they instead responding to the needs of the bureaucracy or the historical administrative structure? Do the laws work as intended? Are they having a positive effect for people with disabilities?

The Americans with Disabilities Act (ADA) is an example of a law that reflects the core precept and the four goals of disability policy. The ADA is intended to ensure that people with disabilities are treated fairly. The U.S. Supreme Court ruled in the *Olmstead* decision that one state was violating the ADA. And it was a warning to all states that they need to pay attention to the Equality of Opportunity principle. Read more about the ADA in *Appendix A: The ADA and Other Examples of Major Federal Legislation that Contain the Disability Policy Framework*.

Bobby says you can start to understand methods of administration by looking at state plans, specifically at *Olmstead* state plans. You should ask yourself if the plans recognize your state’s history, the prevalence of disability, and the real needs of people with disabilities. Then you should look at implementation: Do the plans actually respond to real people’s needs?

An Advocacy Plan

This section will help you understand how to apply the knowledge you gain throughout these modules to real world problems of interest to you.

The Disability Policy Framework lays the groundwork for advocating for better quality of life for individuals with disabilities. The modules that follow will describe the U.S. Supreme Court decision, known as *Olmstead vs. L.C.*, and its implications for people with disabilities living in the community. In order to tie all the modules together and enable you to integrate what you have learned, we encourage you to develop an advocacy plan based on an issue or problem you see or experience. Identify a problem or issue relating to a person with a disability that you want to change. This issue may be the goal you wrote down on page 1 of this module. The following planning model will provide guidance for you as you work on your advocacy goal(s).

Four Steps

There are four steps to constructing an advocacy plan in this planning model. The four steps are: 1) Take stock, 2) Set goals, 3) Develop strategies and take action, and 4) Document progress. These steps can be repeated as many times as necessary to reach a goal.

- 1. Take stock:** Review the situation. Find out what has led to the problem or issue. Identify what action may have been taken previously and what the results were. Bobby Silverstein recommends taking time to “understand the history,” which refers back to the checklist question, “Do we know the history?”
- 2. Set goals:** Identify a specific and measurable outcome that you would like to see happen. Specify goals that are consistent with the core precept (disability is a natural part of human experience; and fix the environment). The more specific the goal, the easier it will be to measure progress. A broad, long-term goal can be broken into smaller steps to better understand and illustrate the planning model.
- 3. Develop strategies and take action:** Decide what action to take. Identify the approach you will use to solve the problem and take action. Develop strategies that are consistent with the four goals of Disability Policy (Equality of Opportunity, Full Participation, Independent Living, and Economic Self-Sufficiency).
- 4. Document progress:** Record the results of the actions that were taken. Are your methods effective? Remember, implementation is what is important. By reviewing the progress that you have documented, you are again “taking stock” of the situation to decide if the actions are bringing you closer to your goal. If progress has not been made, repeat the steps of the planning cycle with new, improved strategies until the goal is completed.

Example

The following is an example of an application to these steps.

Advocacy Goal: Assist Joe in obtaining transportation in the community to go to work.

Take stock: Joe lives in an apartment one block from Main Street. There is a public bus system in his city, but there are not enough accessible buses on every route. Joe has an opportunity for a job across town, but he must take the public bus system to get there.

Set goals: Joe’s advocates want to get an accessible bus route on Main Street so Joe can take the bus to work. They have set the goal to persuade the public Transit Authority to schedule accessible buses along Main Street, at least during commuter times when Joe is traveling to and from work.

Develop strategies and take action: Joe and his advocates decide on some action steps consistent with the four goals of disability policy that they need to take to work toward their goal: a) Find out the process used by the public bus system to determine accessible routes. b) Attend the Transit Authority’s advisory committee that discusses transportation for people with disabilities. c) Write letters to the Transit Authority general manager about the need for an accessible route on Main Street.

Document progress: Joe and his advocates meet to review their efforts, record the results of each of their actions. Are the authorities responding to the requests? If so, are these actions that have been implemented responding to Joe's needs? This action takes them back to the first step of "taking stock," which may then lead to the rest of the steps. After they take stock, they will see how they may need to change the goal and develop alternate strategies, etc.

Application and Discussion

1. Review the goal you wrote at the beginning of this module. Discuss how this goal may be related to public policy.
2. Scenario: John is in an institution and wants out. He has cerebral palsy, and needs support for eating, toileting, and bathing. He used to hold a job as a telemarketer and could still make calls with the correct equipment. List some of the barriers you may face in advocating for John.

These modules will assist you to be able to develop a strong plan for addressing the barriers and challenges you may face in advocating for John.

3. Appendix A lists examples of major federal legislation that include core concepts of the Disability Policy Framework. Review Appendix A to learn more about the core concepts and the legislation.

Beyond the Framework – What's Next?

Summary

In this module you learned about the views of the old paradigm. In the new paradigm you learned about the two concepts of the core precept which are that disability is a natural part of the human experience and the approach is to fix the environment and not the individual. You also heard Bobby explain the four goals of Disability Policy which are; One: Equality of Opportunity, Two: Full Participation, Three: Independent Living, and Four: Economic Self-Sufficiency.

To go along with these principles, you were given checklist questions to help you decide if the goal you are working with is strong in all of these areas.

Preview of Modules

The *Olmstead and Community* modules will help you understand more about implementation of the Disability Policy Framework:

Module 2-IL: Olmstead for 'Newbies' provides background for understanding U.S. Supreme Court decision, known as *Olmstead vs. L.C.*, and what it means for people with disabilities.

Module 3: Consumer Direction: Taking Control explores Goal Three: Full Participation, by describing ways people with disabilities can be involved with decisions that affect their lives.

Module 4-IL: Getting People Out of Nursing Homes and Other Institutions provides real experiences of two advocates from Texas and Kansas in moving people from institutions into the community.

Modules 5a and 5b: Medicaid Framework discusses how the state Medicaid program is implemented and it's potential to provide essential health care and social supports needed by people with disabilities.

As you complete these modules, you will increase your knowledge of how the goals of disability policy are being implemented in your community—and how you can advocate to ensure that your particular goals can be achieved.

Olmstead and Community

Module 2-IL: Olmstead for 'Newbies'

The Olmstead Decision—Background and What It Says and Means

Workbook

Introduction

The story begins with two women, Lois Curtis and Elaine Wilson, who lived in an institution in Georgia and who wanted to move into their own homes. Lois and Elaine were people with disabilities and the State of Georgia said it would be too expensive for the state to support them to live in the community. Lois and Elaine sued the state, and eventually the highest court in the land heard their case.

In this module you will learn about an important U.S. Supreme Court decision known as *Olmstead vs. L.C.* that was made in June of 1999. The Olmstead decision has the potential to make a huge difference in the choices that people with disabilities make to live in the community. This module proposes some actions that centers for independent living and other advocates can take to make these choices available.

Objectives

With this module, you will be able to listen to Lois and Elaine tell some of their story and the challenges they faced. You will listen to an audio recording of an interview conducted by Richard Petty of ILRU (Independent Living Research Utilization) in June 2001. Hearing their story will help you to better understand the U.S. Supreme Court decision, *Olmstead vs. L.C.* Along with Lois and Elaine's story, you will read information that will help you:

- Know the background on the U.S. Supreme Court decision, *Olmstead vs. L.C.*
- Learn the importance of the Olmstead decision for people with disabilities who want to live in the community by understanding what the decision says and means.
- Understand insights from an article on the name and meaning of the Olmstead decision.
- Understand the role that Centers for Independent Living can play in implementing the Olmstead decision.

Lois and Elaine (The Background)

In order to gain a better understanding of the interview, first read the biography of Lois Curtis and Elaine Wilson.

Biography

Lois Curtis and Elaine Wilson

Lois Curtis and Elaine Wilson, two women with disabilities who lived in a Georgia state hospital, asked state officials to allow them to move into their own homes in the community. After the state's refusal, Atlanta Legal Aid attorney Susan Jamieson filed a lawsuit on behalf of Ms. Wilson and Ms. Curtis. In the lawsuit, they again sought to have the State of Georgia allow the two hospital residents to live in the community. After appeals, the case was heard by the U.S. Supreme Court.

The two Georgia women with disabilities (mental retardation and mental illness) claimed that living in a nursing home deprived them of their rights under the Americans with Disabilities Act (ADA) to live in an integrated community setting. *[For more information on the ADA see Appendix A: The ADA and Other Examples of Major Federal Legislation that Contain the Disability Policy Framework.]*

Lois and Elaine argued that they had a right to receive services in a community-based setting under Title II of the ADA. The law requires public entities to provide their services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities... [that] enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible."

The state argued that Lois and Elaine were placed in state-run institutions to obtain needed services. Physicians for the women disagreed, stating they could receive appropriate services while living in the community.

In July 1999, the Supreme Court issued the *Olmstead vs. L.C.* decision. The Court ruled in favor of Lois and Elaine, affirming that where individuals live must be appropriate to their needs and can include home and community-based arrangements. The Court noted that institutionalizing a person with a disability, who wants to live in the community and can benefit from it, is discriminatory.

Interview

Play the video, Module 2-IL, Section 1: "Interview with Lois and Elaine" (6 minutes).

For your convenience, we have included captions of each of the photos you will see during the interview. After the section, stop the video and proceed to the exercises.

Captions for photographs listed in order of appearance:

1. *Three women at a table, (from left to right) Lois Curtis, Sue Jamieson, Elaine Wilson. Sue Jamieson is their attorney, from Atlanta Legal Aid, which brought the lawsuit.*
2. *In front of news camera, (from left) Elaine Wilson, Lois Curtis.*
3. *Tourists walking in Washington, D.C., (from left) Elaine Wilson, Lois Curtis.*

4. *Celebrating the tenth year anniversary of passage of the Americans with Disabilities Act on July 26, 2000, (from left) Lois Curtis, Georgia Governor Roy Barnes, and Elaine Wilson.*
5. *Celebrating victory after the announcement of the U.S. Supreme Court decision, June 22, 1999.*
6. *Legal team in front of U.S. Supreme Court on the day of the oral arguments.*
7. *Same as photo 1.*

(Photos were obtained from Atlanta Legal Aid.)

Stop the video and proceed to the exercises below.

Application and Discussion

1. What did Lois and Elaine want so much that they went to court to get it?
2. Do you know people like Lois and Elaine in your community? Where do they live?
3. What are Lois and Elaine's lives like now? What advice do they give?

What the Decision Says:

Victory

On June 22, 1999, the United States Supreme Court held in *Olmstead vs. L.C.* that *the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability*. The court ruled that the Americans with Disabilities Act may require states to provide community-based services rather than institutional placements for individuals with disabilities.

The decision is a victory in several ways because it supports the following:

- ***Most integrated setting:*** It upholds the U.S. Department of Justice's regulations, which mandate that a state must administer its programs in the most integrated setting appropriate to the needs of individuals with disabilities.
- ***Unjustified isolation:*** It states that unjustified isolation is considered discrimination under the ADA.
- ***Secure community living opportunities:*** It recognizes that Congress intended the ADA to continue earlier efforts in the Developmental Disabilities Act and Rehabilitation Act to secure community living opportunities for people with disabilities.

*[Advocacy and Protection, 2001, Available Online:
www.protectionandadvocacy.com/lcsummar.htm.]*

For more information on these federal laws, see Appendix A: The ADA and Other Examples of Major Federal Legislation that Contain the Disability Policy Framework.

Requirements

Rather than merely affirming (agreeing with) the lower court's decision, the Supreme Court put a number of requirements on the states when they place individuals in the community. Specifically, the Court held that a state:

- ***Must provide services in a fair and equal manner:*** A state must consider the cost of providing community-based care to individuals, and the range of services the state provides to others with mental disabilities. The state has an obligation to provide those services in a fair and equal manner.
- ***May rely on assessments of its own professionals:*** A state may generally rely on the reasonable assessments of its own professionals in determining whether an individual meets the eligibility requirements for a community-based program (see *For More Information* at the end of this module).
- ***Is protected by law if meets requirements:*** A state that has a comprehensive working plan for placing persons with mental disabilities in less restrictive settings, and a waiting list that move[s] at a reasonable pace, is protected in a lawsuit.

Application and Discussion

1. Why would living in an institution be considered “isolating?”
2. Does the Olmstead decision mean that everyone living in an institution can immediately move to the community?
3. Why is having a *working* Olmstead plan important for a state?

What the Decision Means

According to ADAPT (American Disabled for Attendant Programs Today), a grassroots advocacy organization, the Olmstead decision changed the debate from “*should* people with disabilities live in the community?” to “*how* to integrate people with disabilities into the community?”

The Supreme Court laid out the "roadmap" that states must follow to develop their integration plans. To comply with the Olmstead ruling, states must show they have comprehensive and effective plans for placing qualified individuals with disabilities in

less restrictive settings. Beyond that, they must show that waiting lists move at a reasonable pace and are not influenced by attempts to keep institutions fully populated.

New Freedom Initiative

On February 1, 2001, President George W. Bush announced his New Freedom Initiative to promote the full integration of people with disabilities into all aspects of American life. The goals of this comprehensive plan include expanding educational and employment opportunities; increasing access to assistive technologies and public accommodations; and providing accessible transportation and housing options for individuals with disabilities.

In June 2001, President George W. Bush signed the Olmstead Executive Order saying that, "the Supreme Court construed Title II of the ADA (Americans with Disabilities Act) to require states to place qualified individuals with mental disabilities in community settings, rather than in institutions when:

- treatment professionals determine that such placement is appropriate
- the affected persons do not oppose such placement
- the state can reasonably accommodate the placement, taking into account the resources available to the state and the needs of others with disabilities."

This executive order paved the way for states to do exactly what the Supreme Court ruled they should do.

The Olmstead decision applies to people with all types of disability -- not only to people with mental disabilities (intellectual and/or psychiatric disabilities), such as Lois and Elaine. The ruling applies to any person with a disability who meets the requirements for living in an institution. Thus, people with physical disabilities, sensory impairments, or other disabilities - who meet the care requirements of a nursing home or similar institution - are covered by the Olmstead decision.

“At Risk” Issue

Some states interpret the Olmstead decision to cover those “at risk” of institutionalization. If individuals might, at some time in the future because of the nature of their disability, need more intense services than they could be considered “at risk” of needing an institutional level of care. For example, an individual with a disability living at home with adequate supports today might be at risk for institutional placement in the future. While there have been some interpretations from federal agencies and courts that support this position, it is not a consensus and a few states are going to court over the “at risk” issue.

Olmstead upholds the integration mandate of the ADA. The Court affirmed the right of individuals with disabilities to receive public benefits and services in the most integrated setting appropriate to their needs. The Supreme Court noted that unnecessary segregation and institutionalization constitute discrimination and violate the Americans with Disabilities Act (ADA) “integration mandate.” The decision presents new opportunities for expanding community-based services and supports for people with disabilities.

In the next section of the video, Bob Williams, former Deputy Assistant Secretary for Aging Disability and Long-Term Care, talks about what the Olmstead decision can mean. Read Bob’s biography and then play the video.

Biography

Bob Williams

On July 23, 1998—the third anniversary of the Americans with Disabilities Act -- Bob Williams became the first American with a significant disability to be appointed the Commissioner of the Administration on Developmental Disabilities in the Department of Health and Human Services. He later became the Deputy Assistant Secretary for Disability, Aging and Long-Term Care Policy under Health and Human Services Secretary, Donna Shalala.

Bob Williams was born with cerebral palsy in Connecticut, about five miles from the state institution. Because he had parents, brothers and sisters, family and friends who believed in him, he never spent a day in the state institution until he volunteered with the Connecticut ARC to help prepare the lawsuit that closed it down. Since that time, Bob Williams has contributed significantly to the development of home and community services. He uses a communication device to express his ideas when he presents his recommendations to the Administration or talks about home and community services to groups of policymakers and advocates, as in the video clip accompanying this manual.

Play the video, Module 2-IL, Section 2: “Vision for the Future” (2 minutes). After Bob finishes, stop the video and proceed to the exercises below.

Application and Discussion

1. Why does Bob Williams say that the ADA and Medicaid are “polar opposites”?
2. Why does he encourage people with disabilities and the aging community to “sit down together”?
3. What does he say is one of the most important things the decision does?
4. How will aging Baby Boomers be different from previous generations?
5. Why does he see this as a resource?

The Decision's Name

In this section you will read an article from Georgia's *Macon Telegraph* and see some of Olmstead's comments on the decision that bears his name. In order to understand who Tommy Olmstead is, read the biography, then the article, and proceed to the exercises following the article.

Biography

Tommy Olmstead

Tommy Olmstead was the Commissioner of the Georgia Department of Human Services. In that position, he represented the State of Georgia in Lois and Elaine's lawsuit against the State.

Article: Georgia Lags in Responding to Olmstead Decision

By Don Schanche Jr.
Telegraph Staff Writer
March 30, 2003

In a battle that is building all over Georgia and the nation, one man's name has become a rallying cry: Tommy Olmstead.

When a crowd of people demonstrated Wednesday in Macon on behalf of people with disabilities, many carried signs bearing a mysterious phrase: "Implement Olmstead Now."

Translation: Release people who are unnecessarily confined in state hospitals and nursing homes.

Olmstead's name turns up everywhere these days in the "disabilities community."

It comes up in connection with every person with disabilities who wants to be released from a nursing home or hospital in Georgia. And the name "Olmstead" is now known in all 50 states, where government officials are busy doing something called "Olmstead Planning," for the release of unnecessarily institutionalized people.

The Bibb County Commission chairman's name comes up because he was a defendant in a lawsuit while he was commissioner of the Georgia Department of Human Resources from 1995 until 1999.

In 1995, Lois Curtis and Elaine Wilson sued for the right to be released from Georgia Regional Hospital in Atlanta, where they had been treated for psychiatric disorders. In 1999, the nation's highest court said that unjustified isolation of people with disabilities inside institutions is discrimination based on disability - a violation of the Americans with Disabilities Act.

The court didn't call for the abolition of institutions for people with disabilities, and acknowledged that states must have some leeway to work within their budgets. But it

established a disabled person's legal right not to be locked in an institution if there is a way to serve that person in their home outside the institution's walls.

Olmstead's name represents a state's unwillingness to acknowledge that right, as well as the legal obligation to do so.

Some wish there were a different name on the case. "I prefer to call it 'Lois and Elaine's case,'" said Joyce Ringer, executive director of the nonprofit Georgia Advocacy Office, which speaks up on behalf of people with disabilities.

"I have to laugh about it," Olmstead said last year. "My name's there because I was commissioner of DHR. If Joe Dokes was commissioner, his name would be there."

But it is Olmstead's name that stuck. And in a way he never anticipated, the Olmstead case may turn out to be Tommy Olmstead's most pervasive legacy.

The Olmstead Decision has become as significant for people with disabilities as "Brown v. Board of Education" was for the civil rights movement.

"It is seen as the Emancipation Proclamation for people with disabilities," says Eric Jacobson, executive director of the Governor's Council on Developmental Disabilities.

According to a recent report from the National Conference of State Legislatures, "As 2002 ended, the vast majority of states were engaged in structured planning efforts around Olmstead. Most states have published their plans or information on their ongoing planning processes on the Internet."

Many advocates believe Georgia lags behind on Olmstead planning because the interests that support nursing home and state hospitals have strong, long-standing political power here. "Georgia in 1978 was 7th or 8th in the country for community funds and now we're 50th," Ringer said. "That really shows the power of the nursing home and institution lobby."

Georgia's sluggish pace in implementing the Olmstead Decision prompted the GAO, Atlanta Legal Aid and several other advocate groups to file a complaint in 2001 with the Office of Civil Rights in the U.S. Department of Health and Human Services.

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Application and Discussion

1. What does the reporter say that Olmstead's name represents?
2. What do some advocates prefer to call the case?
3. What do you think it should be called?

4. What do Georgia advocates believe is the reason that the state has not implemented Olmstead planning?
5. Do you know how much your state pays to institutions and how much is spent on providing services in the community? How can you find out?

The Role of Independent Living Centers

Many people in the independent living movement believe that centers can and should play a leading role in assisting people to live in the community and helping people leave institutions. Read Mike Oxford's biography below and listen to him as he describes the role centers can play.

Biography

Mike Oxford

Mike is the Executive Director of Topeka Independent Living Resource Center, Inc. and was President of the National Council on Independent Living (NCIL). He is a leader in ADAPT and is committed to "freeing our people" from nursing homes and institutions.

Play the video, Module 2-IL, Section 3: "Where I Got Started" (6 minutes). When Mike finishes, stop the video and proceed to the exercises below.

Application and Discussion

1. What do many people in the independent living movement believe should be the "fifth core service"?
2. What is your center or organization doing to keep people out of institutions/nursing homes or moving people out of institutions/nursing homes?
3. Can you think of other ideas that you can implement in your community? Make sure to put down everything you can think of. Each idea can generate more.
4. What organizations in your community can you partner with in these activities? For example, UCP, ARC, PTC, etc. What perspectives do they bring?

Beyond Olmstead—What’s Next

In this module you read about the background on the Olmstead decision where Lois Curtis and Elaine Wilson who were denied the right to live in their own homes in the community. A lawsuit was filed and eventually the case went all of the way to the Supreme Court. The Supreme Court ruled in favor of Lois and Elaine, affirming that where individuals live must be appropriate to their needs and can include home and community-based arrangements.

The Olmstead decision says that the unnecessary segregation of individuals with disabilities, in institutions, may constitute discrimination based on disability. This means that the Supreme Court laid out the “roadmap” which states must follow to develop their integration plans which also means that independent living centers and you can benefit from these requirements in developing advocacy plans.

You also obtained advice from Mike Oxford, the Executive Director of Topeka Independent Living Resource Center, Inc., on how to access resources to help in your advocacy plans.

Module 3: Consumer Direction: Taking Control, introduces you to consumer direction, self-determination, and consumer control, or ways that consumers can have a say in what their services are and how they are provided. It will compare consumer-directed services to professionally-managed services and will discuss supports that may be available to help consumers direct their own services.

For More Information

For more specific information on what independent living centers can do to get people out of nursing homes, see Module 4-IL in this series: “Getting People Out of Nursing Homes and Other Institutions.”

This manual contains excerpts from the article *Flight to Freedom: Introducing Institutionalized People with Disabilities to Community Living Alternatives* by Steven Brown. The full article is available at:

<http://www.ilru.org/ilnet/files/reading/freedom.html>

Olmstead and Community

Module 2-T: Olmstead for Students and Families

The Olmstead Decision—Background and What it Says and Means

Workbook

Introduction

The story begins with two women, Lois Curtis and Elaine Wilson, who lived in an institution in Georgia and who wanted to move into their own homes. Lois and Elaine were people with disabilities and the State of Georgia said it would be too expensive for the state to support them to live in the community. Lois and Elaine sued the state, and eventually the highest court in the land heard their case.

In this module you will learn about an important U.S. Supreme Court decision known as *Olmstead vs. L.C.* that was made in June of 1999. The Olmstead decision has the potential to make a huge difference in the choices that people with disabilities make to live in the community. This module proposes some actions that centers for independent living and other advocates can take to make these choices available.

Objectives

With this module, you will be able to listen to Lois and Elaine tell some of their story in an audio recording of an interview conducted by Richard Petty of ILRU (Independent Living Research Utilization) in June 2001. Hearing their story will help you to better understand the U.S. Supreme Court decision, *Olmstead vs. L.C.* Along with Lois and Elaine's story, in this module you will read information that will help you:

- Understand the background on the U.S. Supreme Court decision, *Olmstead vs. L.C.*
- Understand more about people's beliefs and misconceptions regarding persons with disabilities.
- Learn how the Olmstead decision was based on the ADA.
- Learn about the importance of the Olmstead decision for people with disabilities who want to live in the community by understanding what the decision says and means.
- Understand how the Olmstead decision can affect your state and your own living situation.

Term Definitions

- **warehouse:** 1. To deposit, store, or stock in or as if in a warehouse. 2. To confine or house (a person) in conditions suggestive of a warehouse. *Merriam Webster Online Dictionary*.
- **integrate:** 1. To make into a whole by bringing all parts together; unify. 2. To open to people of all . . . groups without restriction. *American Heritage Dictionary 2000*.
- **sheltered workshop:** A segregated place of work for persons with disabilities originally designed with contracted jobs (i.e., package dog food—line jobs). People do not have a choice regarding their preference for jobs. Some workshops are more diverse in activities—some have recreation.

Background

In the background section you will read about how people use to view persons with disabilities and how, throughout history, organizations began to emerge to advocate for change. The focus of the advocacy was that services and supports should be provided in the community not just in institutions or nursing homes. You will also read about the challenges of getting services in the community versus nursing homes. You will get to hear a little bit about what life is like in these “homes” from Tony Records, and hear some of the myths about nursing homes from Mike Oxford.

Life Before Olmstead

For many years, our society has viewed people with disabilities as being unable to care for themselves. People who had severe physical or mental disabilities were thought to need constant supervision and care. In order to provide this care in an efficient manner, people with disabilities were often warehoused in nursing homes or other institutions.

Advocacy Organizations Emerge

However, throughout history, some individuals have fought against this notion of people with disabilities as being helpless, dependent, and in need of constant supervision and care. In more recent years, these individuals have become organized through centers for independent living and advocacy organizations such as ADAPT (American Disabled for Attendant Programs Today).

These organizations have argued that while people with disabilities do need assistance in self-care tasks, they are entirely capable of knowing what kind of assistance they need and can direct and supervise the person providing the assistance. This assistance does not need to be provided in a nursing home or in an institution. Personal assistance can be provided in one’s own home.

Federal Organizations Would Not Pay in Community

However, federal programs that helped pay for services (Medicaid and Medicare) often would not pay for services provided in the community, but generally would pay for services provided in a nursing home. Therefore, people who could not afford to pay for

personal care services themselves were forced to go into a nursing home in order to receive basic services.

Advocates knew that it would be less expensive to provide people with services in their own homes. They knew that very few people needed constant care and they knew that nursing homes did not provide 24-hours of actual services.

Life In a Nursing Home

Many people, including some professionals and lawmakers, as well as many people with disabilities and their family members, believe that people receive better care and are safer in a nursing home. They believe that if people with disabilities who need personal assistance services lived in the community, something might happen to them. Is this really true?

Tony Records, the President of Tony Records and Associates, Inc., a human services consulting firm, will describe a typical day in a nursing home on the first section of the video and then Mike Oxford will talk about the belief that nursing homes are safer than living in your own home.

Read Tony's and Mike's biographies and then play the video Section 1: "A Day in the Life" and "Putting Things in Place."

After Tony and Mike finish, stop the video and proceed to the exercises following.

Biography

Tony Records

Tony Records has 30 years of experience in services and supports for people with disabilities. He has served as a Consultant with the Office for Civil Rights of the U.S. Department of Health and Human Services to assist in evaluating states' planning documents for complying with the Olmstead decision. Since 1992, he has been the President of Tony Records and Associates, Inc., a human services consulting firm in Bethesda, Maryland.

Biography

Mike Oxford

Mike Oxford is the Executive Director of Topeka Independent Living Resource Center, Inc. and was President of the National Council on Independent Living (NCIL). He is a leader in ADAPT and is committed to "freeing our people" from nursing homes and institutions.

Play the video, Module 2-Transition, Section 1: "A Day in the Life" (3 minutes), and "Nursing Homes= Safe?" (2 minutes). When the section is finished, proceed to the exercises below.

Application and Discussion

1. How has society viewed persons with disabilities?
2. Why were people forced to go into nursing homes?
3. How does Tony describe life in a nursing home?
4. Why did Tony think that people in nursing homes sleep so much? Why did he leave at 8:30 p.m.?
5. Who did the resident have the longest conversation with?
6. Why did the nurse say the resident had a good day?
7. Are nursing homes safer than the community? Why or why not?

The ADA (Americans with Disabilities Act)

The Americans with Disabilities Act (ADA) was a huge breakthrough for persons with disabilities. The Olmstead decision was based on the ADA. In 1990, President George H.W. Bush signed the ADA into law. Title II of the ADA prohibits state and local governments from discriminating against people with disabilities in the provision of public benefits and services (e.g. public education, employment, transportation, recreation, health care, social services, courts, voting, and town meetings).

The regulations implementing the ADA state:

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))

The regulations defined the “most integrated setting” as “*a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.*” (28 C.F.R. pt. 35, App. A, p. 450)

Advocates were able to use the Americans with Disabilities Act to challenge states that would only provide extensive care and supports in institutions. This meant that the only options for people with disabilities were to live in segregated settings. Advocates argued

that states were not following the law because they were only providing services in segregated settings. One of these challenges—*Olmstead vs. L.C.*—went all the way to the Supreme Court.

Application and Discussion

1. If “segregate” is the opposite of “integrate,” what does “segregate” mean?
2. Discuss situations in which people with disabilities have been segregated. Have you ever experienced segregation?

The Olmstead Decision

Lois and Elaine

Now that you have some historical background on people’s attitudes toward people with disabilities, and you understand how the ADA made the Olmstead decision possible, we will give you the background and the story of the Supreme Court’s decision on Olmstead. In the next segment of the module, you will be able to hear an interview with Lois Curtis and Elaine Wilson. In order to gain a better understanding of the interview, first read their biography.

Biography

Lois Curtis and Elaine Wilson

Lois Curtis and Elaine Wilson, two women with disabilities who lived in a Georgia state hospital, asked state officials to allow them to move into their own homes in the community. After the state's refusal, Atlanta Legal Aid attorney Susan Jamieson filed a lawsuit on behalf of Ms. Wilson and Ms. Curtis. In the lawsuit, they again sought to have the State of Georgia allow the two hospital residents to live in the community. After appeals, the case was heard by the U.S. Supreme Court.

The two Georgia women with disabilities (mental retardation and mental illness) claimed that living in a nursing home deprived them of their rights under the Americans with Disabilities Act (ADA) to live in an integrated community setting. *[For more information on the ADA see Appendix A: The ADA and Other Examples of Major Federal Legislation that Contain the Disability Policy Framework.]*

Lois and Elaine argued that they had a right to receive services in a community-based setting under Title II of the ADA. The law requires public entities to provide their services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities... [that] enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible."

The state argued that Lois and Elaine were placed in state-run institutions to obtain needed services. Physicians for the women disagreed, stating they could receive appropriate services while living in the community.

In July 1999, the Supreme Court issued the *Olmstead vs. L.C.* decision. The Court ruled in favor of Lois and Elaine, affirming that where individuals live must be appropriate to their needs and can include home and community-based arrangements. The Court noted that institutionalizing a person with a disability, who wants to live in the community and can benefit from it, is discriminatory.

Interview

Play the video, Module 2-Transition, Section 2: “Interview with Lois and Elaine” (6 minutes). For your convenience we have included captions of each of the photos you will see during the interview. After the section, stop the video and move on to the exercises following.

Captions for photographs listed in order of appearance:

1. *Three women at a table, (from left to right) Lois Curtis, Sue Jamieson, Elaine Wilson. Sue Jamieson is their attorney, from Atlanta Legal Aid, which brought the lawsuit.*
2. *In front of news camera, (from left) Elaine Wilson, Lois Curtis.*
3. *Tourists walking in Washington, D.C., (from left) Elaine Wilson, Lois Curtis.*
4. *Celebrating the tenth year anniversary of passage of the Americans with Disabilities Act on July 26, 2000, (from left) Lois Curtis, Georgia Governor Roy Barnes, and Elaine Wilson.*
5. *Celebrating victory after the announcement of the U.S. Supreme Court decision, June 22, 1999.*
6. *Legal team in front of U.S. Supreme Court on the day of the oral arguments.*
7. *Same as photo 1.*

(Photos were obtained from Atlanta Legal Aid.)

Stop the video and read the information below before proceeding to the exercises.

Interesting Facts

- In the Supreme Court Decision, written by Justice Ruth Bader Ginsberg, the Court noted that the State’s own experts agreed that Lois and Elaine could be placed in community settings with the proper supports.

[Read the Court’s decision at: http://www.law.emory.edu/11circuit/apr98/97-8538.man.html#N_2_]

- Tommy Olmstead was the Commissioner of the Georgia Department of Human Resources. In that position, he represented the State of Georgia in Lois and Elaine’s lawsuit against the State. "I have to laugh about it," Olmstead said in an article in the Macon Telegraph. "My name's there because I was commissioner of DHR. If Joe Dokes was commissioner, his name would be there." (Don Schanche Jr., March 30, 2003)

- It is important to note that the Olmstead decision not only applies to people with mental disabilities (intellectual and/or psychiatric disabilities), such as Lois and Elaine. The ruling also applies to any person with a disability who meets the requirements for living in an institution. Thus, people with physical disabilities, sensory disabilities, or other disabilities – who meet the care requirements of a nursing home or similar institution – are covered by the Olmstead decision.

Application and Discussion

1. What did Lois and Elaine want so much that they went to court to get it?
2. Do you know people like Lois and Elaine in your community? Where do they live?
3. What are Lois and Elaine’s lives like now? What advice do they give?
4. Some advocates believe that the decision should be called the “Lois and Elaine” decision rather than the Olmstead decision. Why do you think they want to call it the Lois and Elaine decision? What do you think it should be called?

What The Decision Says:

On June 22, 1999, the United States Supreme Court held in *Olmstead vs. L.C.* that *the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability*. The court ruled that the Americans with Disabilities Act may require states to provide community-based services rather than institutional placements for individuals with disabilities. Information listed below shows how the decision benefits people with disabilities.

The decision is a victory in several ways because it supports the following:

- ***Most integrated setting:*** It upholds the U.S. Department of Justice's regulations, which mandate that a state must administer its programs in the most integrated setting appropriate to the needs of individuals with disabilities.
- ***Unjustified isolation:*** It states that unjustified isolation is considered discrimination under the ADA.
- ***Secure community living opportunities:*** It recognizes that Congress intended the ADA to continue earlier efforts in the Developmental Disabilities Act and Rehabilitation Act to secure community living opportunities for people with disabilities.

[Advocacy and Protection, 2001, Available Online: www.protectionandadvocacy.com/lcsummar.htm]

What the Decision Means

According to ADAPT (American Disabled for Attendant Programs Today), a grassroots advocacy organization, the Olmstead decision changed the debate from “*should* people with disabilities live in the community?” to “*how* do we integrate people with disabilities into the community?” The decision means that freedom and independence are possible.

This is what the Olmstead decision means according to Advancing Independence Modernizing Medicare and Medicaid (AIMMM):

“In 1999 the U.S. Supreme Court found the ADA forbids states from institutionalizing people with disabilities of any age if they can live in the community with the right mix of cost efficient community living services.”
(<http://www.aimmm.org/updates.html#nick>)

Yes, freedom and independence are possible, but advocating can be hard work. Some states are lagging behind in implementing the Olmstead decision and making community-based services available to people with severe disabilities. One such case involved Nick Dupree, a young man in Alabama. Read about his challenges and think about what the Olmstead decision can mean in your life.

Story

Nick is a junior at Spring Hill College where he maintains a 3.5 grade average. He is also a quadriplegic who uses a ventilator. Nick was receiving services under a Medicaid program intended to provide care for children. These services allowed him to live at home with his mother and brother and to attend school. Nick learned that when he turned 21 (February 2003), he would no longer be eligible to receive these services. He would be eligible to receive services under an adult program; however, the adult program did not provide the same number of hours or the same types of nursing services that he had been receiving. He would go from receiving 16 hours of care a day to receiving 2 hours of care a day.

The only alternative offered by the state was to provide Nick with services in a nursing home. The closest nursing home that would accept a patient on a respirator and provide some level of services was in Louisiana, 195 miles away from Nick’s family and friends. He would have to quit school and his other activities and become isolated.

Nick would not accept either of these options. “If nothing is done,” he wrote on his web site, “more families will continue to be stuck between a rock and a hard place, forced to choose between quitting their jobs and taking on the responsibility of caring for their loved one 24/7, becoming fatigued and putting their loved one at risk of death or neglect, or sending their loved ones hundreds of miles away to an institution where they may die without supervision. Families should never be put in this position.”

“For medically fragile individuals, going unattended for an extended period of time is not only dangerous but also possibly fatal. For someone like me on life support for example, you need 24/7 supervision to make sure that if your air tube comes off, someone will be

there to put you back on. In nursing homes, constant supervision cannot be provided because often there's 1 nurse to 20 or more patients. A new study has concluded that 9 out of 10 nursing homes are not staffed adequately enough to provide for their patients' basic needs. Institutions are a dangerous place to be, especially for someone with my level of need.”

Nick began a two-year campaign to bring about change and ensure services not only for himself but also for others, including his brother, Jamie.

He documented his efforts on his web site. He wrote letters and raised public awareness of the situation. He worked with his state senator to develop and introduce legislation that would eliminate the age limit on services. When that bill was defeated, he continued fighting through other avenues. He filed a lawsuit in federal court, much like the suit filed by Lois and Elaine.

Nick’s crusade got the attention of Henry Claypool and Bob Williams of AIMMM [Advancing Independence Modernizing Medicare and Medicaid.]. They, along with hundreds of their friends, family, and allies wrote to President Bush, urging him to take action on Nick’s behalf.

Days before Nick’s 21st birthday, federal officials approved a Medicaid waiver program for Alabama that would provide in-home care to Nick and 29 other disabled Alabamians. The waiver is restricted to people who received expanded benefits before age 21 and is limited to 30 participants.

Although this waiver will help Nick, it does not solve the problem of community-based services for all people with disabilities in his state. He says, “I want people to think about the larger problem here. I plan to keep working on this for the rest of my life so that everyone can be safe and can be included in the community—and not locked in a faraway nursing home awaiting their death.”

Story from “Officials OK Medicaid Benefits for Dupree,” Sallie Owen and Sean Reilly, Mobile Register, February 12, 2003.

What the Olmstead Decision Means to Me as a Person With a Disability

The Olmstead decision means that you have the right to live in your own home and community and receive services. The integration mandate of the ADA not only applies to health care services, but to all publicly-funded programs. Most youth with disabilities are not at risk of being placed in an institution to receive health care, such as Nick was.

However, many may find themselves facing other kinds of segregated programs, such as sheltered workshops or other forms of segregated employment settings. Title II of the ADA protects the rights of individuals with disabilities to access public services in the most integrated settings.

Youth in transition and their families should be knowledgeable about how Title II of the ADA applies to other areas addressed in transition planning such as transportation, community living, employment, assistive technology, education, and housing.

In the past, people with disabilities who needed help to work were often employed in segregated settings and sheltered workshops. Supported employment is a new kind of program that matches a person's interest and abilities with jobs in the community. Instead of working in a sheltered workshop, more people are working in regular businesses with the help of a job coach and their co-workers. Through this program, people with disabilities are integrated and accepted into the community. Work, as well as transportation, community living, etc., are important issues to think about as you develop your transition plan and think about what you will do when you finish school.

Application and Discussion

1. In your opinion, did the federal government demonstrate support for the Olmstead decision by approving the Alabama waiver quickly? Could government officials have done more?
2. How did the Olmstead decision help Nick in his crusade?
3. Nick fought a two-year campaign and even then didn't give up when things looked bad. What can you learn from his experience?
4. As a person with a disability or as a family caring for a loved one with a disability, what can you do when you are faced with the dilemma of you or your loved one going to work in a sheltered workshop or work in other places that are segregated?
5. What are some things you can do to get ready to live and manage your own services in the community? Write down all of your ideas. Invite others to brainstorm with you.

Beyond Olmstead—What's Next

In this module you read about the background on the Olmstead decision where Lois Curtis and Elaine Wilson were denied the right to live in their own homes in the community. A lawsuit was filed and eventually the case went all of the way to the Supreme Court. The Supreme Court ruled in favor of Lois and Elaine, affirming that where individuals live must be appropriate to their needs and can include home and community-based arrangements.

The Olmstead decision says that the unnecessary segregation of individuals with disabilities, in institutions, may constitute discrimination based on disability. This means that the Supreme Court laid out the "roadmap" which states must follow to develop their integration plans which also means that independent living centers and you can benefit from these requirements in developing advocacy plans.

You also obtained advice from Mike Oxford, the Executive Director of Topeka Independent Living Resource Center, Inc., on how to access resources to help in your advocacy plans.

You also learned about Nick Dupree's battle to live in the community with the supports he needed and how he used the Olmstead decision to his advantage. His advocacy plan aligned with the checklist questions in *Module 1: Disability Policy Framework*. He was able to get the supports he needed—besides helping some others gain supports they needed for a time.

Module 3: Consumer Direction: Taking Control, will introduce you to consumer direction, self-determination, and consumer control, or ways that consumers can have a say in what their services are and how they are provided. It will compare consumer-directed services to professionally-managed services and will discuss supports that may be available to help consumers direct their own services.

For More Information

Mapping Your Dream Series—Home Living

<http://www.pacer.org/tatra/MYD-HomeLiving.htm>

Adolescent Autonomy Checklist, Developed by the Youth in Transition Project,
University of Washington Division of Adolescent Medicine

http://depts.washington.edu/healthtr/checklist_print.doc

The Illinois Division of Specialized Care for Children's list of transition resources

<http://internet.dsc.uic.edu/dsccroot/parents/transition.asp>

Olmstead and Community

Module 3: Consumer Direction: Taking Control

Workbook

Introduction

“The day the agency sent another new aide to assist me was the time I finally decided to take charge of my life. This was the sixth different aide that I had had in four weeks. They were all nice and willing to help, but I was tired of training them! With my disability, it is very difficult for me to move and I need assistance in just a certain way. It would take me several days (and a lot of unnecessary pain) before the aide was able to position me correctly. Then the aide would be gone and I had to start with another one. My neighbor in the apartment upstairs had always been willing to assist me when I needed help and I realized that if I could pay her as a personal assistant, then I would have a lot more consistency in my life and less stress.”

What you just read is an example of a person who decided to plan and direct her own services. She realized she could have control and she could practice consumer direction.

Objectives

In this module, you will learn about consumer direction. Consumer direction means that as an individual with a disability, you can plan and direct your own services. Individuals with disabilities have been requesting greater control over their own services in recent years. This module explains why many consumers want to direct their own services, and also describes some of the supports that are available for consumer direction.

Self-determination and consumer control are related concepts. By increasing your understanding of these approaches, you can advocate for more consumer direction, self-determination, and consumer control in your community. These are the key principles you will learn:

- Understand the philosophy of consumer direction.
- Learn about the related concepts of self-determination and consumer control.
- Learn how home and community services can be provided through consumer direction.
- Learn more about advocacy issues in consumer direction.
- Compare consumer-directed approaches with professionally-managed services.
- Understand the supports that may be available to help consumers who desire to direct their own services.

Term Definitions

- **self-determination:** “Determination of one’s own fate or course of action without compulsion; free will.” *American Heritage Dictionary*.
- **consumer direction:** When a person needing services (a “consumer”) is allowed to arrange and supervise (i.e., “direct”) the services they receive.

Consumer Direction

“Nothing about us without us.” Quote by -- Judy Heumann

As you read before, consumer direction means that as an individual with a disability, you can plan and direct your own services. Within this section, you will read about the factors that influenced the expansion of consumer direction and you will get to hear Suzanne Crisp define consumer direction.

Expansion of Consumer Direction

Consumer direction did not occur suddenly, but rather was the result of advocacy and pressures within society itself. Benjamin (2001) identifies these as:

- Three decades of aggressive advocacy by non-elderly persons with disabilities increased political pressure to expand publicly-funded, personal-assistance services that give consumers more autonomy to direct their own care.
- Consumer movements called for the “demedicalization” of some conditions (such as disability, old age, and pregnancy) and services (such as supportive home care and childbirth) so the message of consumer direction has a broader context.
- Concerns about the costs of long-term care made federal and state policymakers receptive to home-based service approaches considered to be less costly. Because consumer direction reduces or eliminates the need for home care agencies and case managers, service costs are expected to be lower.
- The recent shortage of front-line workers also increased receptivity to new strategies for recruiting long-term care providers. For example, if recipients can hire family and friends as workers, this may help to address widespread difficulties in attracting workers to low-paying jobs in home care.
- The Supreme Court’s 1999 Olmstead decision has put additional pressure on states to consider diverse approaches to providing community placements and services for persons with disabilities.

Advocacy pressures, cost issues, and lack of personnel in traditional services have all been instrumental in providing more opportunities for consumers to direct their own services.

Defining Consumer Direction

Read Suzanne Crisp’s biography and listen as she discusses and defines consumer direction and self-determination in this section of the video.

Biography

Suzanne Crisp

Suzanne directed a Cash and Counseling Demonstration Project in Arkansas that enabled participants to gain greater control in decision-making, including hiring their own workers, determining which services they need, along with how much service they actually receive. Suzanne is currently the Senior Research Leader for The MEDSTAT Group and is engaged in addressing a variety of fiscal management services for persons with disabilities who choose to direct their own services.

Play the video, Module 3, Section 1: “What is Consumer Direction?” (5 minutes).
When she is finished, proceed to the exercises below.

Application and Discussion

1. Towards the beginning of the module some factors that contributed to the expansion of consumer direction were listed. What are some other factors in our country today that are helping the movement toward greater consumer control and direction?
2. How is quality of life enhanced by consumer direction?
3. What is your opinion of Judy Heumann’s description of self-direction: “It’s not doing things by yourself, but being in charge of how things are done?”
4. When Suzanne Crisp was describing the stereotypes for elderly people who needed care, she sarcastically used this statement: “It’s okay to be a mind reader for an aged person.” What does this mean?
5. Are consumers the best judge of what their needs are *and* the approach to meeting those needs? Why? Why not?
6. Can you provide an example of an instance where you were the best judge of your needs? And an instance when you weren’t the best judge of your needs?
7. What is a cross-disability advocate?
8. In each of the scenarios below, what are these people practicing?
--An elderly person who has severe arthritis and can’t cook has an aide help her fix her favorite recipes.

--A man who uses a wheelchair hires his nephew to come by each morning and help him get ready for work.

--A young woman with cognitive disabilities has hired her sister to help her balance her checkbook and make her weekly grocery list.

--Parents of a child with a disability have employed the child's aunt to help bathe and dress her each day.

Self-Determination and Consumer Control

Before looking at specific steps for achieving consumer direction, we will briefly discuss the philosophy of other related concepts that Suzanne mentioned in the video: self-determination and consumer control. These terms reflect a consumer focus in services and advocacy that is having a significant impact on home, school, and community services for people of all different ages with all types of disabilities. After that, we will examine how these concepts are a critical component of transition.

It is important to understand that the values underlying these interrelated concepts are the same: A person with a disability should be a full participant in their community and have control over the types of services they receive and how these services are provided.

Self-Determination

The idea behind self-determination is that a person with a disability, regardless of the severity of the disability, has choices, preferences, and dreams. These choices, preferences, and dreams must be respected and should also serve to guide the services and support that people need. The skills that promote self-determination include self-management, self-advocacy, choice making, problem solving, decision-making, and goal setting.

With the opportunity of self-determination, also comes responsibility that can sometimes be frightening. Some may ask "So, as a person with a disability, do I have to do everything?" People with disabilities should not have to make all their decisions by themselves, just as people without disabilities rely on others to support them.

In self-determination, an individual may invite friends and family members (in a "circle of support") to assist in directing and managing services. Various methods have been developed, such as "person centered planning," to help the person clarify and express his personal preferences.

"Person centered budgeting" is an approach to help the person use public resources to help achieve their goals. The person's legal representative, family members, or substitute decision-maker may assist and advise the individual and help with management tasks.

Consumer Control

NOTE: Consumer control is an extension of family-centered care philosophy first used by the Federal Maternal and Child Health Bureau in working with children and youth with special health care needs.

Self-determination and consumer control are not totally different. Consumer control is just another way of describing who should be in charge.

- Consumer control implies that individuals with disabilities should have control over their own services based on their choices, preferences, and dreams.
- Consumer control means that the power and authority within organizations that provide services to enhance independence and to advocate for social change should be directed by consumers.
- Individuals with disabilities should have the power to decide the priorities and the activities of the organization in overcoming the community barriers encountered by its consumer population.
- In the school system, the “parents as expert” philosophy means that for younger children, the special education services should be designed and guided by the family who know their child best and a team of qualified professionals.

Self-Determination: A Critical Component of Transition

The transition from school to work and community is one of the first times in their life when youth have the opportunity to assume a more adult role and thus, more responsibility and control. To promote self-determination during transition, it is important for families and the person’s support system to:

- Assist students to develop greater self-awareness and to learn decision-making.
- Provide opportunities for youth and young adults to learn other skills that they need to plan their future, such as goal setting and negotiating.
- Allow youth to make decisions and experience consequences of their actions. By doing this they can learn the skills needed to become self-directed.

What’s exciting is that the Individuals with Disabilities Education Act (IDEA) Amendments of 1997 clearly support student self-determination. IDEA requires that:

- Students are involved in the development of their individualized education program (IEP) as members of their own IEP teams and that they attend their IEP meetings as an active participant.
- Student’s educational programs must be based on the student’s preferences and interests.

As the philosophy of consumer direction becomes integrated into more and more disability programs and policies, it is important for youth to develop these crucial skills. Consumer direction is not just a concept for health services. It applies to a broad range of services and supports for persons with disabilities.

Application and Discussion

1. What do you think about Judy Heumann’s quote “Nothing about me without me?” How does this relate to the old paradigm? To the new paradigm?

2. Have you heard the term ‘self-determination’ used in another context? What does it mean to you? Is there a self-determination project in your state?
3. At the Center for Independent Living, several consumers serve on the Board of Directors and are responsible for setting the governing policies and priorities for the center. Is this an example of consumer direction?
4. Can you see evidence of consumer control in organizations you belong to? Explain.
5. How effective are your local schools in supporting self-determination for youth and young adults? Can you think of examples?
6. What are some strategies that parents can use to assist youth to assume consumer direction in their lives? Is this a simple one-step process? Why? Why not?
7. Scenario: John is 29 years old and has lived in a nursing home since he was 10 years old. He has a severe spinal cord injury and needs oxygen, uses a wheelchair, and cannot speak. He has a head pointer and a communication board. He wants to live in the community.

How easy do you think it would be for John, who has not been accustomed to making decisions himself, to become self-directed? What problems do you think he may experience? Provide examples.

What role might a CIL play in helping John learn the skills he will need to live in the community? Can you think of specific activities for advocates to help John?

Consumer-Directed Home and Community Services

Home and community service programs funded by Medicaid are frequently criticized for operating under a so-called “medical model” or professionally-managed model. In this model, professionals decide what services will be provided, how they will be provided, and who will provide them.

Many individuals with disabilities feel that current agency-directed approaches for home and community services do not meet their needs. Consumer direction is a trend that separates needs for medically trained providers from needs for routine daily living supports. All people have preferences for how personal-care tasks should be done. The consumer direction philosophy says consumers should have more control and choice in their own routine daily living supports.

One of the most commonly used services required by individuals living in the community is personal assistance. Personal assistance refers to *non-medical services* that a person

in managing his money. Marty receives SSI and has a job stocking parts at a hardware store. Marty lived with his mother in the family home until she died last year. A social worker from Community Support Agency arranged for a person-centered planning meeting with Marty's friends to figure out how Marty could get the help he needs and remain as independent as possible. The biggest challenge was figuring out how to pay for support services because Marty did not qualify for Medicaid home and community services. The social worker helped Marty write a PASS plan to enable Marty to hire an assistant to help with his medications, the household bills, and home maintenance so he could continue to live in his home.

Consumer as Employer: A Big Responsibility

As an increasing number of people with disabilities choose the consumer-directed approach, they have found that new skills are needed to be the employer of the worker(s) who provide services. If you think about what it means to be an employer, there are a lot of responsibilities. Individuals who want greater self-direction need to understand the extent of the responsibility involved with being an employer.

Table 1 lists the tasks that are necessary to employ a person to perform personal assistance services.

COMPARISON OF CONSUMER-DIRECTED SERVICES WITH PROFESSIONALLY-MANAGED SERVICES
<p>Recruiting/Hiring/ Firing</p> <p>In Consumer-Directed Services the consumer locates, interviews potential workers, makes hiring decision, and may fire worker.</p> <p>In Professionally-Managed Services the agency recruits, hires, assigns worker, and may fire worker.</p> <p>Supervising/ Scheduling</p> <p>In Consumer-Directed Services the consumer tells worker what to do, negotiates schedule, evaluates performance.</p> <p>In Professionally-Managed Services the agency establishes worker tasks, sets staff schedule, evaluates worker performance.</p> <p>Training the Worker</p> <p>In Consumer-Directed Services the consumer is responsible for training worker in specific job duties.</p> <p>In Professionally-Managed Services the agency is responsible for training worker in general job duties.</p> <p>Paying the Worker</p> <p>In Consumer-Directed Services the consumer is responsible for worker paychecks, payroll taxes, filing government reports.</p> <p>In Professionally-Managed Services the agency is responsible for worker paychecks, payroll taxes, filing government reports.</p> <p>Setting Provider Qualifications</p> <p>In Consumer-Directed Services the consumer sets qualifications (within Medicaid requirements).</p> <p>In Professionally-Managed Services the agency sets qualifications (within Medicaid requirements).</p> <p>Decisions About Quality</p> <p>In Consumer-Directed Services the consumer decides if he/she is satisfied with worker performance.</p> <p>In Professionally-Managed Services the agency has quality standards (within regulations) for worker performance.</p>

Table 1. Comparison of Consumer-Directed Services with Professionally-Managed Services.

Application and Discussion

1. What is exciting about consumer-directed services for consumers? Families? CIL staff?
2. What is challenging about becoming an employer? For consumers? Families? CIL Staff?
3. Should all services be consumer-directed? Why? Why not?

4. If a youth with a disability has difficulty communicating their wants and needs, is consumer direction still possible?

Myths of Consumer Direction

A consumer-directed, federal demonstration project known as *Cash and Counseling* has been tested in three states (Arkansas, Florida, and New Jersey). In this model, consumers receive a monthly cash allotment that can be used to purchase any services or goods they consider essential.

Early reports suggest that some consumers make very different choices than typical professional choices. Consumers used the cash for home modifications and furniture purchases that facilitate mobility but are not covered by Medicaid. Recipients can manage cash directly or pay a small fee to have a certified fiscal agent manage the funds. Most have chosen to use the fiscal agent. The counseling part of the program involves peer professionals who are available to provide consumers with information to enable them to make informed decisions.

Watch Suzanne Crisp discuss the myths about consumer direction that she has encountered in her experience in the *Cash and Counseling* program in Arkansas.

Play the video, Module 3, Section 2: “Myths about Consumer Direction” (2 minutes).
Then proceed to the exercises.

Application and Discussion

1. Do the myths reflect the old paradigm or the new paradigm? Why?
2. How would you respond to each of the myths? Are they myths or are they truths? Write M for myth or T for truth.

Misuse of money

Abuse and exploitation

Not interested

Lack ability

Health will decline

Too vulnerable

Case managers know best

Agency services are superior

3. Why did you answer the way you did? Have you or anyone you know had experiences with people believing some of the myths?

Consumer Direction Supports

Many states and communities have been trying out various ways to support consumers who want to have more control over their services, yet do not want to take on all of the responsibilities. Some consumers are afraid of the risks involved with consumer direction, while others feel they don't have the necessary knowledge and skills.

There are agencies that can help individuals who are willing to take on some consumer direction tasks. Supports for consumer direction can lessen the risks and burdens on the consumer or family. Not all of these supports may be available in your community, so you will have to investigate to find out what is available. The supports we will discuss are supports for coordinators (brokers, agents, and counselors), recruiting and hiring, scheduling, training, paying workers, and setting worker qualifications.

- **Coordinators (Brokers, Agents, and Counselors):** Assistance for individuals in managing and directing their home and community services and supports can be provided by paid professionals who are variously termed service coordinators, support brokers, personal agents, or counselors. This new terminology underscores the philosophical differences between professional case/care management as typically practiced and supporting individuals in directing and managing their own services. Assistance can also be provided through peer counselors and staff at independent living centers.
- **Recruiting and Hiring:** Public programs may help in identifying potential personal assistants by maintaining a worker "registry" or list of available or qualified candidates. Programs may help the consumer perform a criminal background check for potential employees.
- **Scheduling:** Consumers negotiate with workers for the times they need them, although Medicaid will limit the maximum number of hours authorized in a time period (e.g., in a month). However, sometimes workers do not show up or the consumer needs emergency assistance. An emergency backup plan should be developed.

Sometimes agencies will agree to be part of a backup plan in emergencies (with the understanding the consumer is responsible for their fee).

- **Training:** Two types of training are available. Training for the consumer to learn how to direct his/her own services may be offered through an independent living center or other community organization.

Training for the personal assistance worker may be available through a local community high school or college, or the Internet, such as Certified Nurse Assistant (CNA) training, or First Aid training.

- **Paying Worker(s):** Consumers who use the self-directed model say that the most difficult task is paying the employee and handling all of the associated paperwork. This paperwork includes preparing paychecks twice monthly, figuring the right amount of payroll taxes to take out, filing reports with the Internal Revenue Service, figuring out how much money is left to pay for services, making reports of how the money was spent, and so on.

Fortunately, some organizations are developing special services to assist consumers with these financial and reporting tasks. There are several terms used for these kinds of organizations. Intermediate Services Organization (ISO) is the term used by the federal Internal Revenue Service. Other terms used are Fiscal Intermediaries, Personal Services Agents, or Fiscal Agencies.

- **Setting Worker Qualifications:** Services that are paid for with Medicaid funds must have minimum qualifications for providers of any service, whether consumer-directed or professionally-directed. Medicaid is a public program and is accountable to taxpayers for how money is spent. But qualifications for providers (workers) are in the domain of the state according to state and local laws and regulations. Your state Medicaid program may have different qualifications for providers within consumer-directed programs than it does for providers in professionally-managed services. We have listed some examples of minimum provider qualifications for personal assistance services; however, you will need to contact a representative of your state Medicaid program to learn what the provider qualifications are in your area.

Examples of minimum provider qualifications for personal assistance services:

- 18 years of age or older.
- Social Security number.
- Ability to understand verbal instructions.
- Ability to record written notes.
- First Aid Certification.
- Willingness to undergo criminal background check.

Remember to check with your state Medicaid agency to find out what the provider qualifications are for a particular Medicaid service. A consumer may require a worker to have other skills or abilities in addition to the basic minimum qualifications for a provider. For example, the ability to transfer a 180 pound adult in and out of bed or to have a driver's license.

An employer (consumer) can require certain qualifications to meet her needs for assistance. Suggestions for relevant provider qualifications may come from other consumers who have used personal assistance.

Application and Discussion

1. Read through the supports for consumer direction. How many of these are available in your community? Is there a registry or list of personal assistants? Do you know what agency(ies) maintain a list? Do you know what agency(ies) maintain a list? Is training or preparation for consumers offered?
2. Invite a consumer who is using one or more of these supports to meet with your group to describe how they work.

3. Does your state offer Fiscal Agent services? Invite a representative of the Fiscal Agency or someone who uses the service, to your group to explain how it works. Ask them to bring a brochure, forms, or a packet of information about Fiscal Agency services.

4. Based on this module, how do you feel about consumer-directed services? Why?

Beyond Consumer Direction—What’s Next?

This module discussed consumer direction, self-determination, and consumer control; or ways that consumers can have a say in what their services are and how they are provided. It compared consumer-directed services to professionally-managed services, and discussed supports that may be available to help consumers direct their own services. Understanding these concepts will help you understand the direction you need to—or want to take in developing your plan for advocacy. For more information on issues for advocacy in consumer direction, see *Appendix C: Issues for Advocacy in Consumer Direction*.

Module 4-IL: Getting People Out of Nursing Homes and Other Institutions will provide real experiences of two advocates from Texas and Kansas in moving people from institutions into the community.

Olmstead and Community

Module 4-IL: Getting People Out of Nursing Homes and Other Institutions

Workbook

Introduction

Julie is 32 years old and has been a resident of Sunshine Valley Care Center for 5 years following an auto accident. Her family was killed in the crash and she had no close relatives to care for her. At first she needed a lot of medical care, physical therapy, and speech therapy. Now she mainly needs help with bathing, getting in and out of bed, and remembering to take her medication for seizures. She hasn't had a seizure for over 6 months, and can sense ahead of time when she is going to have one.

A few months ago Julie heard about a program to help Sunshine residents move out of the nursing home. Julie didn't sign up for the program because the staff told her that she needs 24-hour care because of her seizures. Julie is disappointed to think she will have to live at a place like Sunshine the rest of her life. . .

Objectives

Julie doesn't have to live in a place like Sunshine the rest of her life. Centers for independent living can play an important role in their states in implementing the Olmstead decision. The Supreme Court decision supports people with disabilities, like Julie, to receive services in the community. This module will provide some practical suggestions on how to get started. In this manual, we use the term "nursing home" to refer to institutions warehousing people with disabilities. Please remember that there are other institutions besides nursing homes in your community, and that the information presented here is intended to apply to all institutions.

With this information you will:

- Understand what a day is like in the life of a nursing home.
- Learn about supports or an "infrastructure" that is needed in the community to enable people with disabilities to live independently outside of institutions.
- Understand some barriers that prevent people from leaving nursing homes.
- Learn strategies to support effective transition from nursing homes.
- Learn some myths associated with nursing homes.
- Learn strategies for obtaining support for people making the transition.

Term Definitions

infrastructure: The underlying foundation or basic framework (as of a system or organization) or the resources (personnel, buildings, or equipment) required for an activity. *Merriam-Webster Online Dictionary.*

over-medicalization: The attitude that all disability issues are really just medical problems and can best be solved by professionals.

ageism: As people become older and acquire disabilities, modifications and assistive technology may not be offered because society considers that as people age, they will naturally lose basic skills and that “it is just part of getting older.”

A Day in the Life of a Nursing Home Resident

Earlier in the module we had talked about the myth that nursing homes are safer than the community. Read Tony Records’ biography and listen as he describes the day he spent with one individual resident who lived in a nursing home.

Biography

Tony Records

Tony Records has 30 years of experience in services and supports for people with disabilities. He has served as a consultant with the Office for Civil Rights of the U.S. Department of Human Services to assist in evaluating states’ planning documents for complying with the Olmstead decision. Since 1992, he has been the President of Tony Records and Associates, Inc., a human services consulting firm in Bethesda, Maryland.

Play the video, Module 4: Getting People Out of Nursing Homes and Institutions, Section 1: “A Day in the Life” (2 minutes).

No one says that moving people with disabilities from institutions to the community is easy. Many, many people, however, say that it is necessary! If you are concerned about convincing the staff and board at your center, the service providers in your community, or your local and state policymakers that it *is* necessary, consider accepting the challenge that Tony Records offers.

Application and Discussion

1. How does Tony describe life in a nursing home?
2. What was the reason Tony surmised that people in nursing homes sleep so much?
3. Why did Tony leave at 8:30 p.m.?
4. Who did the resident have the longest conversation with?

5. Why did the nurse say the resident had a good day?

Building an Infrastructure of Support

In order for people with disabilities to remain in their own homes or to move out of nursing homes, supports have to be available in the community. Making sure that these supports are available involves building an *infrastructure*.

The infrastructure needed to support people with disabilities to live independently in the community includes the following resources:

- Housing,
- Benefits (such as SSI, SSDI, Medicaid, Medicare),
- Community access (including transportation), and
- Personal assistance.

Many centers for independent living are already involved in building an infrastructure through their systems advocacy efforts. Read Bob Kafka's biography and then listen to the video as he describes the strategy that ADAPT (American Disabled for Attendant Programs Today) used to identify and coordinate local resources.

Biography

Bob Kafka

Bob Kafka, co-founder of Texas ADAPT (American Disabled for Attendant Programs Today, a grassroots advocacy organization), is a nationally recognized leader in the disability rights movement. His commitment to in-the-streets, in-your-face advocacy and civil disobedience has contributed to such victories as the passage of the Americans with Disability Act, the introduction of Medicaid Community-Based Attendant Services and Supports Act (MiCASSA), and the granting of state Medicaid waivers.

Play the video, Module 4: Getting People Out of Nursing Homes and Institutions, Section 2: "On Community" (2 minutes). When the section is finished, proceed to the exercises below.

Application and Discussion

1. Which pieces of the infrastructure (housing, benefits, community access, etc.) are present in your community? Describe them. Which pieces are missing?
2. How can your center/organization help put those pieces in place?

Barriers and Transition

The thought of building an infrastructure, to support people with disabilities coming out of institutions, can be daunting. Note that the transition process will involve changes not only in the community, which may be one barrier, but it will

involve changes for the individual and the way he or she looks at the options and risks. This can be another barrier.

In the next portion of the video, Bob Kafka and his colleague, Mike Oxford, describe how they approach this issue one person at a time. Leaving an institution for the community is a complicated process and involves having the specific personalized supports available in the community and also effectively meeting an individual's concerns. Bob and Mike each describe barriers as well as successful strategies for addressing the barriers as well as planning transition activities. Mike will also describe three steps involved in helping a person make a successful return to the community:

- Identify people who want to live in the community.
- Understand why they went into the nursing home, what supports were missing.
- Provide support for emotional, social, and physical needs.

Read Mike Oxford's biography below and then listen as Bob and Mike talk about their approach to tackling the transition process one person at a time.

Biography

Mike Oxford

Mike Oxford is the Executive Director of Topeka Independent Living Resource Center, Inc. and was President of the National Council on Independent Living (NCIL). He is a leader in ADAPT and is committed to "freeing our people" from nursing homes and institutions.

Play the video, Module 4: Getting People Out of Nursing Homes and Institutions, Section 3: "One Person at a Time" (20 minutes). When the section is finished, proceed to the exercises below.

Application and Discussion

1. Wouldn't it be easier just to move everyone at the same time from a nursing home into the community? Why? Why not?
2. Do you really have to be a rocket scientist with a Ph.D. to get people out of institutions/nursing homes? What skills do you need?
3. According to Bob, why don't people just wake up one day and say, "I want to move out of the nursing home?"
4. Why is inviting people to participate in community activities, before moving out, important?

5. Why is a peer support network important for people coming out of institutions/nursing homes?

The Myth: Nursing Homes are Safe and Communities are Dangerous

As Bob and Mike have noted, some professionals, as well as many people with disabilities and their family members, believe that people receive better care and are safer in a nursing home. Is this really true?

Listen to what Mike Oxford says about the myth that nursing homes are safer.

Play the video, Module 4: Getting People Out of Nursing Homes and Institutions, Section 4: “Nursing Homes = Safe?” (2 minutes). When the section is finished, proceed to the exercises.

Application and Discussion

1. Are nursing homes safer?
2. What are some things that push people into institutions/nursing homes?
3. Do you know people who had to go into an institution/nursing home, but didn't want to? What pushed them into an institution/nursing home?
4. Are families always happy to have their spouse/child/relative move out of a nursing home? Why? Why not?

Support for Transition

In the video both Bob and Mike are very frank about the fact that it requires a lot of resources to get even one person out of a nursing home. The center also has to be prepared to help consumers deal with sticky and complicated situations, such as family members who may be overprotective or who have their own reasons for not wanting to have the person at home. This may involve the court system in cases where guardianship or divorce is an issue.

In addition, helping a person to make the successful transition from life in a nursing home to life in the community involves a continued commitment of resources *after* the person has moved out of the institution. Mike estimates that an average of 90 days or 3 months of intensive support (involving staff time and other resources) are required *after* the consumer has moved into the community.

Topeka Independent Living Resource Center, Inc. has been successful in identifying sources of support that do not cost them a lot of money.

Listen to Mike as he describes some of the creative approaches he used to obtain housing and furnishings for people whom his center has helped move out of nursing homes. Notice also, at the end of the video section, that he talks about some handouts produced by the Topeka Independent Living Resource Center: the “Going Home” brochure and the

“Move Out/Freedom Plan,” which includes a checklist of the items an individual needs in order to move into the community. These materials are included in your packet and are also available online. (See *For More Information* at the end of the module).

Play the video, Module 4: Getting People Out of Nursing Homes and Institutions, Section 5: “Low Cost Resources” (5 minutes). When the section is finished, proceed to the exercises below.

Application and Discussion

1. Discuss the concept of “over-medicalization.” Have you seen examples of this?
2. What is “ageism”? Does this affect the number of people going into nursing homes?
3. Is it important to invite people living in nursing homes to community activities? Is there a potential problem?
4. On the average, how long will Centers for Independent Living or other organizations need to provide intensive emotional and physical support to someone who has moved out of an institution/nursing home?

Beyond Getting People Out of Nursing Homes—What’s Next?

In this module we listened to helpful advice from Bob Kafka and Mike Oxford about building an infrastructure within the community in order to ensure that the people have the supports they need. We looked at some of the myths of nursing homes versus what nursing homes are really like.

To help us gain a better insight into additional supports that may be available, we will look at Medicaid. *Modules 5a and 5b: Medicaid Framework* discusses how the state Medicaid program is implemented and its potential to provide essential health care and supports needed by people with disabilities.

For More Information

At the end of video Section 4, Mike talked about some handouts produced by the Topeka Independent Living Resource Center: the “Going Home” brochure and the “Move Out/Freedom Plan,” which include a checklist of the items an individual needs in order to move into the community. As mentioned before, these materials are included in your packet and are also available online:

Going Home brochure: <http://www.tilrc.org/docs/advocates02.htm>

Move Out/Freedom Plan, including checklist: <http://www.tilrc.org/docs/advocates05.htm>

Olmstead and Community

Module 4-T: Staying in the Community

How the Olmstead Decision and the ADA Assist Young Adults to Live and Work in the Community

Workbook

Introduction

For almost 30 years, the IDEA or the Individuals with Disabilities Education Act (previously the Education of All Handicapped Children Act) has ensured that children, youth, and young adults (ages 3 through 21) receive a free and appropriate education. The school system has provided special education and related services as well as providing a place to be 7 hours a day, 5-days a week for at least 9 months each year. As young adults exit the school system, either through graduation or a certificate of completion, the world of services and supports changes dramatically. Adult services and supports are often disability and program specific, fragmented, and scarce.

However, in spite of these challenges, young adults should be able to live full, productive lives in their communities or a community of their choice. The first, and most significant concept is “staying in the community.” There are two important reasons why staying in the community is increasingly possible for young adults: (1) the impact of the Olmstead decision, and (2) the guiding principles established by the Americans with Disabilities Act (ADA).

Objectives

With this lesson you will better understand how the ADA, as well as the Olmstead decision, help young adults stay in the community. Some of the challenges that must be addressed to stay in the community will be discussed as well as new supports and incentives that encourage young people with disabilities to be part of the workforce. In this section you will:

- Learn how the Olmstead decision was possible with the ADA.
- Learn about the challenges of some young adults to live in the community.
- Understand the concept of “dignity of risk”.
- Learn about work incentives for young adults.

Term Definitions

public entity: Any state or local government (including public school), or private organization which operates programs funded by government with taxpayer dollars.

work disincentive: Something that discourages a person from working such as losing supports or benefits (i.e., SSI check or Medicaid card).

Olmstead is for More Than Just Lois and Elaine

You have heard the story of Lois Curtis and Elaine Wilson, the two women who lived in a Georgia institution and wanted to live in the community. Their fight for freedom resulted in the 1999 U.S. Supreme Court Olmstead decision. The decision was a victory for all people with disabilities, not only people with mental disabilities like Lois and Elaine. The Supreme Court was interpreting the Americans with Disabilities Act (ADA), and the ADA prohibits discrimination against people with disabilities regardless of their type of disability.

The Supreme Court said that unjustified segregation is discrimination. In other words, segregation without a good reason is against the law. Lois and Elaine were being kept in a Georgia state hospital even when their own doctors said they should be let out. So the Court ruled that Georgia violated the ADA, and the decision applies to all states throughout the U.S.

The decision is important because the Court upholds the integration requirement of the ADA. The integration requirement of ADA Title II says:

A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. [28 CFR Section 35.130(d)]

This requirement applies to any government funded service, program, and activity – not just institutional care. By upholding the integration requirement, the Supreme Court opened the door for people with disabilities to claim their rights to integration in other public services. You don't have to live in a state hospital, like Lois and Elaine, to assert your rights to integrated services. Public schools, public transportation, public employment programs, public housing – they are all covered by the ADA Title II.

You may know a person with a disability, who is living in the community, who would need institutional care if they did not receive support to live at home such as a personal care attendant, nursing care, respite care, etc. Such individuals are considered to be “at risk” of institutional placement. Under the ADA's integration requirement, they should receive services in the “most integrated setting appropriate to their needs.” The Olmstead decision's support for the ADA's integration requirement has given impetus to advocacy efforts for more accessible, integrated community services. Advocates for both institutionalized persons and those at risk of being institutionalized have a common interest in working together.

Application and Discussion

1. Scenario: Lon is 19, has a moderate intellectual impairment, and lives with his parents. He attends a segregated workshop program supported by the local school district. Lon would like to get his own job and use public transportation rather than having to take the school bus, as he did in high school. Lon's parents would like Lon to become more independent, but at the Transition IEP (individual education plan) meeting the school officials said the workshop is all they have. The parents are dismayed that Lon is still doing the same things at school he did when he was 16.

Does the "integration requirement" of ADA apply to Lon? Why? (Remember Title II applies to government funded services, even if those services are provided by a private organization.)

2. Scenario: Elroy is 23, has multiple disabilities, and lives with his father and grandmother. He uses a manual wheelchair, is legally blind, and has severe hearing loss. Recently his father was diagnosed with terminal cancer, and his grandmother is very worried how she will take care of herself and Elroy if his father dies. Elroy does not receive any public services since he finished high school, but he is on a waiting list for a personal care Medicaid waiver service.

Is Elroy at risk of institutional placement? Does the ADA integration requirement apply to him? Why or why not?

What Advocates Can Do

People with disabilities, their family members, and advocates can make sure that their state officials know of the Supreme Court's mandate and comply with the decision. In most instances, compliance will mean that the state develops a "comprehensive, effectively working plan for placing qualified persons in less restrictive settings." Consumers and advocates must insist on meaningful input into this plan. Beyond input, consumers and advocates must be prepared to react if the elements of the plan are not implemented. This is a big job and is larger than any one person. Advocates are encouraged to work in coalitions with other consumers and disability organizations to increase the chance that their voices are heard. Visit this link for more information:

<http://www.protectionandadvocacy.com/sumforpacket.htm>

Youth at Risk of Leaving the Community

For youths with disabilities, most will remain in their community (or choose another community) and move on with their lives after completing their school years. However, for a number of young adults, remaining in the community can be problematic for several interrelated reasons including the limited Medicaid benefits available to adults in the community, lack of appropriate housing and individualized services, and family concerns.

Medicaid

As a young adult, an individual with a disability must qualify for Medicaid based on their own income, not their parents. So it is sometimes easier for them to get Medicaid. However, the benefits provided under Medicaid to adults are much more limited than those for children. This may mean that the health related supports and services will not be available in the amount or frequency required. Often, to get the amount and type of services provided by Medicaid, an individual with a disability may feel that moving to an institution is the only solution.

Lack of Individualized Supports (Person-Centered Services)

Adult services are fragmented, limited, and often provided only in group settings. Individualized supports—and especially those provided in the home or at the job site—are available only on a limited basis. In order to develop and implement a support system for an individual, multiple services and funding streams must be accessed and coordinated.

Some services are extremely limited and difficult to access for adults with limited incomes. Mental health services, medications, and dental and vision services are examples of these.

With all of these challenges, it can be an uphill battle to continue to live in the community. In *Module 2-T: Olmstead for Students and Families*, we learned about Nick Dupree, a teenager from Georgia who just wanted to continue his life with his family and friends in his community; but had to go court to do it. Because of the impact of Nick's message, please reread the story and then proceed to the exercises.

Family Concerns

When a young adult has a disability requiring intensive daily supports (such as tracheotomy, respirator, assistance with toileting, eating, dressing, etc.), families may feel the safest place for their “child” is a congregate setting where staff will be available 24/7. Providing the care that the person needs may seem overwhelming, particularly as the parents become older or their families face other challenges. In some situations, members of the family may not want to commit themselves to a lifetime of supporting their adult child or sibling.

At a different level, many parents worry that their adult child, with a significant disability, will not be able to function effectively in their community and will be vulnerable to abuse, violence, or persecution. From their perspective, their adult child should be protected in an institution or nursing home.

Story

Nick is a junior at Spring Hill College where he maintains a 3.5 grade average. He is also a quadriplegic who uses a ventilator. Nick was receiving services under a Medicaid program intended to provide care for children. These services allowed him to live at home with his mother and brother and to attend school. Nick learned that when he turned 21 (February 2003), he would no longer be eligible to receive these services. He would

be eligible to receive services under an adult program; however, the adult program did not provide the same number of hours or the same types of nursing services that he had been receiving. He would go from receiving 16 hours of care a day to receiving 2 hours of care a day.

The only alternative offered by the state was to provide Nick with services in a nursing home. The closest nursing home that would accept a patient on a respirator and provide some level of services was in Louisiana, 195 miles away from Nick's family and friends. He would have to quit school and his other activities and become isolated.

Nick would not accept either of these options. "If nothing is done," he wrote on his web site, "more families will continue to be stuck between a rock and a hard place, forced to choose between quitting their jobs and taking on the responsibility of caring for their loved one 24/7, becoming fatigued and putting their loved one at risk of death of neglect, or sending their loved ones hundreds of miles away to an institution where they may die without supervision. Families should never be put in this position."

"For medically fragile individuals, going unattended for an extended period of time is not only dangerous but also possibly fatal. For someone like me on life support for example, you need 24/7 supervision to make sure that if your air tube comes off, someone will be there to put you back on. In nursing homes, constant supervision cannot be provided because often there's 1 nurse to 20 or more patients. A new study has concluded that 9 out of 10 nursing homes are not staffed adequately enough to provide for their patients' basic needs. Institutions are a dangerous place to be, especially for someone with my level of need."

Nick began a two-year campaign to bring about change and ensure services not only for himself but for others, including his brother, Jamie.

He documented his efforts on his web site. He wrote letters and raised public awareness of the situation. He worked with his state senator to develop and introduce legislation that would eliminate the age limit on services. When that bill was defeated, he continued fighting through other avenues. He filed a lawsuit in federal court, much like the suit filed by Lois and Elaine.

Nick's crusade got the attention of Henry Claypool and Bob Williams of AIMMM [Advancing Independence Modernizing Medicare and Medicaid]. They, along with hundreds of their friends, family, and allies wrote to President Bush, urging him to take action on Nick's behalf.

Days before Nick's 21st birthday, federal officials approved a Medicaid waiver program for Alabama that would provide in-home care to Nick and 29 other disabled Alabamians. The waiver is restricted to people who received expanded benefits before age 21 and is limited to 30 participants.

Although this waiver will help Nick, it does not solve the problem of community-based services for all people with disabilities in his state. He says, "I want people to think about

the larger problem here. I plan to keep working on this for the rest of my life so that everyone can be safe and can be included in the community—and not locked in a faraway nursing home awaiting their death.”

Story from “Officials OK Medicaid Benefits for Dupree,” Sallie Owen and Sean Reilly, Mobile Register, February 12, 2003.

Application and Discussion

1. What types of services and supports did Nick need to live in the community?
2. Why would things change when Nick turned 21? Where would Nick need to go to receive services?
3. How would you feel if this were your child? If this were you?
4. Will your adult child be able to live in the community? What are the supports that he or she will need? What are the barriers? Write down all of your ideas. Invite others to brainstorm with you.

Safety and the Dignity of Risk

Safety

Many people, including professionals and lawmakers, as well as some people with disabilities and their family members, believe that people receive better care and are safer in a nursing home. Families and professionals often focus on the safety of the individual with a disability. *Safety is important and should always be considered.* However, it is important to recognize that institutions and nursing homes do not always provide safety. Patients do not receive 24-hour attention and patients are often alone and lonely.

Tony Records, the President of Tony Records and Associates, Inc., a human services consulting firm, will describe a typical day in a nursing home on the first section of the video.

Read Tony’s biography and then play the video, Section 1, “A Day in the Life” (3 minutes).

Biography

Tony Records

Tony Records has 30 years of experience in services and supports for people with disabilities. He has served as a Consultant with the Office for Civil Rights of the U.S. Department of Health and Human Services to assist in evaluating states’ planning documents for complying with the Olmstead decision. Since 1992, he has been the President of Tony Records and Associates, Inc., a human services consulting firm in Bethesda, Maryland.

Play the video, Module 4: Getting People Out of Nursing Homes and Institutions, Section 1: “A Day in the Life” (3 minutes).

Dignity of Risk

Safety is always important to consider. However, there is also the dignity of risk that allows people to learn and grow. Read Robert Perske’s biography and then read the brief article written by him that helps to explain dignity of risk.

Biography

Robert Perske

Robert Perske is widely known for his work on behalf of people with disabilities. Bob actively tracks, works with, and writes about persons with mental disabilities who were coerced into confessing to murders they did not commit. His recent books include *Circles of Friends*, *Unequal Justice*, *Deadly Innocence*, and *Show Me No Mercy*. He has written and contributed to reports presented to Presidents Nixon and Carter. In 1999, he was honored by The National Historic Preservation Trust on Mental Retardation as one of 35 persons who made major contributions in the field of mental retardation in the 20th century.

Both Bob and Martha Perske have made major contributions toward changing the world's view of persons with disabilities, thereby helping them to lead better, richer lives.

Article: Dignity of Risk

Overprotection may appear on the surface to be kind, but it can be really evil. An oversupply can smother people emotionally, squeeze the life out of their hopes and expectations, and strip them of their dignity.

Overprotection can keep people from becoming all they could become.

Many of our best achievements came the hard way: We took risks, fell flat, suffered, picked ourselves up, and tried again. Sometimes we made it and sometimes we did not. Even so, we were given the chance to try. Persons with special needs need these chances, too.

Of course, we are talking about prudent risks. People should not be expected to blindly face challenges that, without a doubt, will explode in their faces. Knowing which chances are prudent and which are not—this is a new skill that needs to be acquired.

On the other hand, a risk is really only when it is not known beforehand whether a person can succeed...

The real world is not always safe, secure, and predictable. It does not always say "please", "excuse me", or "I'm sorry". Every day we face the possibility of being thrown into situations where we will have to risk everything...

In the past, we found clever ways to build avoidance of risk into the lives of [sic] persons living with disabilities. Now we must work equally hard to help find the proper amount of risk these people have the right to take. We have learned that there can be healthy development in risk taking... and there can be crippling indignity in safety!

From: "Hope for the Families" By Robert Perske.

Application and Discussion

Safety

Please answer the following questions regarding safety from what you heard from Tony Records.

1. Was the woman that Tony describes “safe”? Why? Why not?
2. Is physical safety the same as emotional safety? What is emotional safety?
3. How is the fact that people in nursing homes sleep so much related to the concept of “safe”?
4. How much direct attention did the patient receive from the nursing staff? Is this 24/7 care?
5. Are nursing homes safer than the community? Why or why not?

Dignity of Risk

Please read the scenarios and answer the following questions about the concept “dignity of risk.”

- Scenario: John is 23 years old and loves to take care of animals. He has several pets and is very responsible about feeding them, taking them for walks, and cleaning-up after them. His job coach would like to help him find a job in a pet store, but he has never learned to take the city bus. John’s parents are afraid that he will miss the bus, get lost, get teased by other passengers, or actually be assaulted.
- Scenario: Deborah is 21 years old and has just completed high school. She is very independent. She takes care of her personal needs, manages her allowance, and has had a part-time job for several years at a bakery. She has several friends from the neighborhood that are now attending the community college and have their own apartment. Deborah has asked her parents if she can move in with them and pay rent since her job at the bakery is now full-time. Deborah has never lived

away from home and her parents are concerned that she will get involved with drugs or alcohol if she is around college students.

1. What are the safety issues? Are these real? Are these just possibilities?
2. How does the “dignity of risk” principle apply in each of these scenarios?
3. Can you describe an example in your own life when you accomplished something by taking a risk (doing something that was new or challenging)?

Working in the Community

The current generation of youth with disabilities and their parents are use to the idea of inclusion. The Individuals with Disabilities Education Act (IDEA) and its predecessor have been in place since 1977 and Section 504 since 1973 (See *Appendix A: The ADA and Other Examples of Major Federal Legislation that Contain the Disability Policy Framework*). Our education system develops expectations among children and youth with disabilities and their families that their adult lives will be spent included in their community. IDEA mandates a person-centered approach to education in the most integrated setting appropriate. Thus young adults with disabilities leave school with expectations of living and working in the community.

Many young adults with disabilities and their families have a rude awakening when they learn the adult service system is fragmented, administered by hundreds of federal, state and local government, and private agencies, and has huge gaps in what is offered. One of the reasons Lois and Elaine were “stuck” in an institution was because of the lack of a coordinated, person-centered system of community supports. The barriers for Lois and Elaine were specifically concerning health care and housing because that is what they needed to live in the community. But as we’ve said earlier, Olmstead is more broadly related to the integration requirement of the ADA for public services.

School is the public service that students with disabilities and parents are most familiar with during childhood and adolescence. Upon reaching adulthood, young adults with disabilities and parents face a whole new world of public programs and supports – a myriad of agencies and programs, differing eligibility rules without entitlements, and great variability among programs from state to state and even from one community to the next. It can be very daunting for individuals and families to understand and navigate through a maze of agencies and programs to find necessary and appropriate services.

A Vision For a Better Work Support System

Advocates with a vision of a better, integrated adult support system, that includes work for individuals with disabilities, persuaded Congress to pass the Ticket to Work and Work Incentives Improvement Act (TWWIIA) in 1999. Nine years after the passage of the ADA, this new law contains a vision for a more person-centered, coordinated, and comprehensive system of supports for adults with significant disabilities who need ongoing supports to work in the community. The TWWIIA law addresses many barriers

to work faced by people with significant disabilities, including work disincentives (i.e., loss of cash and health care benefits) and the lack of coordination among the many federal and state assistance programs. The TWWIA legislation was signed by President Clinton but has the strong support of the current Republican administration.

The list below describes some of the important provisions of the TWWIA law. As advocates for individuals with disabilities, you need to find out which provisions are available in your state and community.

Medicaid Buy-In: State legislatures and Medicaid agencies can change their state's Medicaid eligibility requirements to include working adults with disabilities. If an adult meets the Social Security standard of disability, he/she can work and earn above the poverty level and continue to receive the health care benefits provided by Medicaid, if needed. Most states that have adopted this buy-in program charge a premium, on a sliding scale for those who qualify, and most have an upper income limit between 250% and 450% of poverty. The buy-in program allows states to change their rules so that working adults with disabilities don't have to live in poverty and can save for retirement and other goals.

To learn if your state has the buy-in, go to:

www.cms.hhs.gov/twwia/statemap.asp

Medicaid Infrastructure Grants (MIG): The Center for Medicare and Medicaid Services (CMS) has awarded grants to states to develop comprehensive, coordinated systems of work supports for individuals with significant disabilities. These grants are intended to help states improve their employment support systems beginning at whatever point a state happens to be. Some states have used MIG funds to develop a Medicaid buy-in program, a benefits counseling program, employer education, and/or outreach to consumers. A strong emphasis of the MIG is to expand personal assistance services. CMS requires a state to demonstrate improvement in personal assistance services that support work for people with disabilities as a condition for continuing to receive a MIG.

To learn about your state's Medicaid Infrastructure Grant, go to:

www.cms.hhs.gov/twwia/inf_dmap.asp

Social Security Work Incentive Changes: There are two cash assistance programs for people with disabilities administered by the Social Security Administration: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). These programs send monthly checks to eligible individuals. The Social Security Administration wants to encourage people with disabilities to work if they are able. Both SSDI and SSI have rules about what happens if a recipient has earned income from work. The rules are very complicated and confusing because many recipients do not know which program they are on. The TWWIA law made some positive changes to work incentives for all of SSDI, SSI, and Medicare. The SSA agency has made

administrative changes in order to provide better knowledge of work incentives by agency claims representatives.

To learn about work incentive rules, go to: www.ssa.gov/work

Benefits Counseling: The Social Security Administration (SSA) has awarded grants to local agencies in each state to develop counseling services for recipients of SSA disability cash benefits (SSDI and SSI) who want to work. The national program is called Benefits Planning Assistance and Outreach (BPAO) and it is for people who are already receiving SSDI and/or SSI benefits and want to know how finding a job and going to work will affect their public benefits. The counseling is not limited to the impact of earnings on cash benefits, but includes advice on health care, housing, transportation, food stamps, or other public benefits. Benefits counseling combined with the SSA work incentive changes have gone a long way in creating a “safety net” for people with significant disabilities who want to work.

To learn about BPAO programs in your state, go to:

www.ssa.gov/work/ServiceProviders/bpaofactsheet.html

Ticket to Work and Self-Sufficiency: Ticket to Work is a program intended to give SSDI/SSI recipients greater choice among service providers to help them return to work or work for the first time. The Ticket promises to provide payment to Employment Networks (approved service providers) if the individual goes off government programs that provide benefits or makes progress toward going off benefits as a result of working. The SSDI/SSI recipient is not subject to continuing disability reviews due to working while using the Ticket.

To learn more about Ticket to Work in your state, go to:

www.yourtickettowork.com

Protection and Advocacy for Beneficiaries of Social Security: Grants are available to each state protection and advocacy agency to assist SSDI/SSI recipients with discrimination issues with employers and public agencies. These grants can also be used for legal assistance to help recipients with overpayment problems with Social Security resulting from changes in earned income.

To learn where the PABSS program is in your state, go to:

www.ssa.gov/work/ServiceProviders/pafactsheet.html

Other Federal Initiatives Affecting Transition

The New Freedom Initiative is an executive order, issued by President George W. Bush in 2000, that promotes inclusion and integration for people with disabilities through many directives to Congress and executive branch agencies. The executive order includes

discussion of transition in many places such as 1) transition from school to work and postsecondary education must be a key part of a state's Olmstead plan; and 2) Olmstead plans should include transition, employment, and technology, not just housing and health care. The executive order is at:

www.whitehouse.gov/news/freedominitiative/freedominitiative.html

New strategies to increase participation of youth in work force development activities are being developed by the Department of Labor Office of Disability Employment Policy (ODEP). These strategies will be implemented through One-Stop Employment Centers and other youth programs authorized by the Workforce Investment Act.

Application and Discussion

1. Does your state have a Medicaid buy-in program? How can advocacy efforts help in getting or improving such a program in your state?
2. Does your state have a Medicaid Infrastructure Grant? What agency administers the MIG? How does the MIG envision a comprehensive, person-centered employment support system for people with disabilities?
3. Who administers the BPAO program in your state? Are benefits planning services available that assist people to understand how their SSDI/SSI benefits will be affected if they work? How can advocates be involved in expanding benefits planning assistance and outreach to help people who want to work?
4. Are you aware of other changes in your state or community that affect the ability of individuals with disabilities to work in their community? What are they? Are they positive or negative? How can advocacy influence these factors?

Beyond Staying in the Community—What's Next?

In this module we learned how the Olmstead was possible with the ADA and about some challenges of Nick Dupree. We talked about the “dignity of risk” and about work incentives for young adults.

To help us gain a better insight into more supports that may be available, we will take a look at Medicaid. *Module 5: Medicaid Framework, Part I and Part II*, discuss how the state Medicaid program is implemented and its potential to provide essential health care and social supports needed by people with disabilities.

For More Information

Mapping Your Dream Series—Home Living:

<http://www.pacer.org/tatra/MYD-HomeLiving.htm>

Adolescent Autonomy Checklist, Developed by the Youth in Transition Project, University of Washington Division of Adolescent Medicine:

http://depts.washington.edu/healthtr/checklist_print.doc

The Illinois Division of Specialized Care for Children’s list of transition resources:

<http://internet.dsc.uic.edu/dsccroot/parents/transition.asp>

The Olmstead Decision and Services for Youth with Disabilities in Community Settings, Transcript of NCSET teleconference call held on March 21, 2002 presented by Robert “Bobby” Silverstein, J.D., Director, Center for the Study and Advancement of Disability Policy and Deborah Leuchovius, National Coordinator, Technical Assistance on Transition and the Rehabilitation Act, PACER Center:

http://www.ncset.org/teleconferences/transcripts/2002_03.asp

ADA Q&A...ADA and Transition

By Deborah Leuchovius, Rachel Parker, and Jane Johnson, PACER Center:

<http://www.pacer.org/tatra/ada.htm>

Center for Health Care Strategies: An Analysis of Olmstead Complaints: Implications for Policy and Long-Term Planning by Sara Rosenbaum, Joel Teitelbaum, and Alexandra Stewart Center for Health Services Research and Policy, The George Washington University Funded by the Center for Health Care Strategies, Inc. under The Robert Wood Johnson Foundation’s Medicaid Managed Care Program. December 2001.

Olmstead and Community

Module 5: Medicaid Framework Part I; History, State Plan, and Services

Workbook

Introduction

In the next two parts of this module, you will learn the fundamentals of the Medicaid program, the federal/state program that is an important source of funding for basic health care services, and long-term supports needed by people with disabilities to live in the community.

In order to *really understand* what Medicaid can do in your state, you will need to learn about your state's unique Medicaid program rules. Invite a representative from Medicaid to meet with you to answer questions about various aspects of the program after you have gone through both parts of this module.

Within each section, you will read information pertaining directly to what you will be listening to in that section of the video and it will help you organize what you hear. You will then be able to listen to the video and afterwards do the exercises. The exercises have two sets of questions pertaining to a given section: One set is for you to answer and another set is for your state representative to help with.

Even though the second set is for your state representative, it would be good for you to be in a group setting to discuss these questions to find out if people you know can answer the questions. You will be able to learn from each other and then focus on the questions you wish to ask your state Medicaid representative. This will make your session with the representative most effective.

Split Module

We recommend that you split this module into two or three sessions: Either learn the separate parts of the module together and have a separate session for the question/answer with your state representative or hold two sessions for each part and another session for question/answer with the representative.

You can obtain written materials and search for specific information on the Internet, but these will not be as helpful as discussing the details with a knowledgeable Medicaid representative. To locate a knowledgeable person(s), begin by asking a local office representative to identify someone who can discuss Medicaid eligibility, state plan services, home and community-based waiver eligibility and waiver services, and issues relevant to transition-aged youth. You may wish to ask the state Medicaid representative to bring any pertinent information.

Objectives

To help you understand Medicaid better, you will listen to Lee Bezanson, the National Project Director of Home and Community-Based Services (HCBS) Resource Network and a Management Associate with The Community Living Exchange at ILRU, talk about the history of Medicaid, the state plan services, benefits, and people who can qualify for services.

This module will help you be able to:

- Learn about the history of Medicaid.
- Learn what services are offered by the Medicaid State Plan in your state.
- Understand how people can qualify for Medicaid in your state.

Term Definitions

imd (institution for mental disease) exclusion: Medicaid does *not* cover inpatient psychiatric services for people between 18-64 years of age.

entitlement: To give a person a just claim or right. *The American Century Dictionary.*

wraparound services: A multiple array of services and supports needed by an individual to live in the community. Typically these are not ‘medical’ services.

The History

As Lee Bezanson will explain in the video, Medicaid has a very interesting history. Medicaid was established as federal law in 1965 and Medicare was enacted in the same year. Lee says, “No one designed Medicaid and it doesn’t make any sense.” The reason she says that is because Medicaid has evolved to meet the changing times and the needs of the people. Some interesting points that have helped Medicaid become what it is today are as follows:

- Since 1965 the private insurance market has systematically eliminated coverage for people who are “high cost” and “high risk.”
- Each time that happened those people have turned to Medicaid.
- New groups, new services, or new waivers were added.
- The Medicaid program has become the health care safety net for people who are unable to obtain insurance anywhere else. This includes primary and long-term health care.
- Each new group had its own eligibility rules and coverage rules. (That’s why it doesn’t make any sense.)

Medicaid is an important source of funding for basic health care services and long-term supports needed by people to live in the community. Some important things to remember about Medicaid are:

- It is a federal-state partnership.
- It is administered by each state under broad federal requirements and guidelines.
- Each state develops its own State Plan.
- The Federal government “matches” State money.
- Match rates vary from state to state.
- It is a *medical* program; it provides medical services and also provides psychosocial supports for certain groups.
- It serves 37.5 million people, including senior citizens, low-income people with disabilities, and adults who are referred to as the working poor (in some states).

Note: Here is a “quirk” in Medicaid: Medicaid does *not* cover inpatient psychiatric services for people between 18-64 years of age. Because waivers are intended to offer alternatives to institutional services, there are no Home and Community-Based Waivers for adults with mental illness. This is called IMD (Institution for Mental Disease) Exclusion.

The State Plan

A State Plan is the written document submitted by your state Medicaid agency. It must be approved by the federal government through the Center for Medicare and Medicaid Services (CMS).

The State Plan describes who can get Medicaid (eligibility) and what services are offered (coverage). There are basic Medicaid services and there are optional services.

Basic Medicaid Services

Basic services are mandatory and must be offered to children and adults who meet the eligibility requirements if a state has a Medicaid program.

Some examples of basic (mandatory) services are:

- Inpatient and outpatient hospital care.
- Laboratory and X-ray services.
- Physician services.
- Immunizations and early periodic screening diagnosis and treatment (EPSDT) for children.
- Home Health Services.
- Nursing home entitlement.

Optional Medicaid Services

Services other than the basics *may or may not* be provided. These are called “optional” services.

There is large variation among states in what is provided (type of services), how much is provided (amount of services), and who is eligible for specific services.

States may choose to provide a number of optional services. Remember that each state exercises a great deal of control over who is eligible for specific services.

Optional services may include:

- Outpatient rehabilitation services.
- Occupational, physical, and respiratory therapy.
- Speech-language-hearing services.
- School-based program for children with special health needs.
- Clinical services, which can include mental health services.
- Assistive technology.
- Targeted case management for individuals with developmental disabilities or mental health needs.
- Personal care services.
- Home medical equipment, orthotics, and prosthetics.
- Dental services.
- Prescription drugs.
- Other health professional services, often targeted to individuals with mental illness or other disabilities.
- Services in institutional and community living situations through the ICF/MR (Intermediate Care Facility for People with Mental Retardation) program.
- Inpatient mental health services for children under age 21.
- Home and community-based long-term supports/services.
- Day treatment and habilitation.

Now that you have a basic understanding of Medicaid’s history, the state plan, and some of its basic and optional services, read Lee Bezanson’s biography and then watch the video to help solidify the principles.

Biography

Lee Bezanson

Lee Bezanson is the National Project Director of Home and Community-Based Services (HCBS) Resource Network and she is a Management Partner with the Community Living Exchange at ILRU. Previous to these positions, she was the Medicaid Director for the State of New Hampshire. She is a psychiatric nurse and an attorney by training.

Play the video, Module 5 Part I, Section 1: “Medicaid State Plan” (7 Minutes). After Section 1 is finished, proceed to the exercises below.

Application and Discussion

Questions for You

1. Who develops the state plan? Why is it important to understand the relationship between state and federal control?
2. Has your state recently changed (either reduced or added) certain optional Medicaid services? What are they?
3. Look at both lists of basic and optional services. What services have you (or someone you know) received? Are there services that you didn't know were paid for by Medicaid?

Questions for the State Representative

1. Refer to the list on page 4 of this module. Are the basic services in your state the same? Are there additional services for youth (under 18)?
2. What *optional* services are offered to youth and adults in your state?
3. What are the general eligibility requirements for Medicaid and how does a person with disability, a youth, or family apply? Is the process the same for all groups?
4. What limitations are imposed by the state (in terms of who can get services and how much they can get)? How are the limitations different for youth services and for adult services?
5. How do these services compare to other health insurance plans that you are familiar with?

6. What is the current state match rate? What does this mean for Medicaid programs?

Medicaid Eligibility

How do you get Medicaid benefits? In order to qualify for services, you need to get the Medicaid card. If you get the card, you are entitled to *all* of the state plan basic services. There are also waivers to qualify for, which we will discuss in the next section of the module.

Lee explains that eligibility for Medicaid is about access through the right door. There are many doors and they are different for children and for adults. You have to find a door to qualify before you can get Medicaid services. Below are some things to remember about the differences between services for children and for adults.

Services for Children

- Medicaid is different for children than it is for adults.
- Medicaid is the largest insurance package in the country for children.
- The law requires states to provide for children a rich package of benefits, known as EPSDT (Early Periodic Screening, Diagnosis, and Treatment).
- States are mandated to screen children periodically.
- Almost everything is covered.
- States must provide any service if it is determined to be *medically necessary for that child*.

The services for children are not utilized as effectively as they could be, but they open the door to do the right thing for children.

Doors (Categories) for Children Who Qualify

- Children with disabilities on SSI.
- Children in low-income households.
- Children in households above the poverty level under special rules (Title 21 programs – Child Health Insurance Program (CHIP)).

The state will normally look at a family's income to determine eligibility (an exception is the Katie Beckett Option).

Note: The Katie Beckett Option is a Waiver option (not available in all states) that allows for Medicaid funding for care at home for children who need institutional level of care. The parents' income is not counted for purposes of Medicaid eligibility under this option.

Services for Adults

The services for adults are not as robust as they are for children, and adults have a smaller package. For example:

- There is no requirement like EPSDT.
- The dental services are better for children than for adults.

Medicaid, however, is the “only act in town” for long-term services for adults.

Doors (Categories) for Adults Who Qualify

- Persons with disabilities on SSI.
- Adults with low-income who have dependent children.
- Adults with low-income who are 65 or over.

An important thing to remember with Medicaid is that if you have private insurance and Medicaid, you must always exhaust your private insurance before Medicaid will pick up the rest of the bill. Wraparound and community-based services for people with disabilities follow this principle.

Wraparound and Community-Based Services

Wraparound services include an array of services and supports that are needed by an individual, not just a single service. These are typically not medical services but are social supports such as transportation, personal assistance, counseling, or service brokering. Medicaid will pick up wraparound and community-based services because Medicaid is the “only game in town.”

Remember, if you have private insurance and Medicaid, you must always try to exhaust your private insurance first. Medicaid is always the payer of last resort. But ironically, when it comes to “wraparound services,” Medicaid is usually the only source of funding.

Play the video, Module 5 Part II, Section 2: “Medicaid Eligibility” (7 minutes). After Section 2 is finished, proceed to the exercises.

Application and Discussion

Questions for You

1. Do you know what “door” you (or someone you know) qualifies under? (Refer to lists previously mentioned for children and adults.)
2. What is the income limit for Medicaid in your state for a single adult? Research your state's Medicaid program on the Center for Medicaid

and Medicare Services (CMS) website. Select your state name and this website will provide you with information about your state's eligibility categories, state plan services, waivers, disability issues, and lots more. <http://www.cms.hhs.gov/medicaid/statemap.asp>

3. In determining income eligibility, a person's assets are also considered. What is the asset limit in your state? What is considered an asset?

Questions for the State Representative

1. What "doors" open to Medicaid in your state? How are they different for youth and adults? How is SSI tied into Medicaid?
2. How many eligibility groups are there for youth and adults in your state?
3. What is the maximum income limit for a person/family to receive Medicaid? Does this change every year? When is a youth's income considered? How much support can a youth receive from their family in the form of housing or income before it impacts their benefits?
4. Where do you go to apply for Medicaid if you are under the age of 18? Over the age of 18?
5. How can a person find out if his/her disability qualifies for Medicaid? Does a youth go through a redetermination process if they are receiving benefits before age 18 and will continue to need them after the age of 18? How will Medicaid coverage change?
6. How can parents find out about the different Medicaid programs available in their state and the country?

Beyond Basic and Optional Medicaid Services—What's Next?

In Part I of this module you were able to learn about the history of Medicaid, the state plan, and the basic and optional services of Medicaid. Hopefully you are gaining a good understanding of the services out in the community, like Medicaid that will help build the infrastructure of services you or those who you are advocating for will need.

In Part II of this module you will learn about Medicaid waivers or services that are provided *in addition to* the state plan services. Waivers are very beneficial for any advocate to know about: they provide exceptions to rules.

Find Out More

An excellent reference for a comprehensive explanation of Medicaid waivers is: *Understanding Medicaid Home and Community Services: A Primer*, by Gary Smith, Janet O'Keeffe, Letty Carpenter, Pamela Doty, Gavin Kennedy, Brian Burwell, Robert Mollica, and Loretta Williams, George Washington University, Center for Health Policy Research, October 2000. To find it on the web go to

<http://aspe.hhs.gov/daltcp/reports/primer.htm>;

Or contact the ASPE Project Officer, Gavin Kennedy, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, SW, Washington, DC 20201. His e-mail address is: gkennedy@osaspe.dhhs.gov.

Olmstead and Community

Module 5: Medicaid Framework Part II; Waivers and Community Supports

Workbook

Introduction

In this module, you will continue on your journey to better understand the fundamentals of the Medicaid program. Make sure to try to understand all you can in the sections as you read and listen to the videos. Then answer all of the questions to the best of your ability to prepare for your meeting with the Medicaid state representative.

Objectives

In Part II of the Medicaid module you will get to listen as Allan Bergman, the President and Chief Executive Officer of the Brain Injury Association, and Lee Bezanson, explain waivers. Waivers are additional services that Medicaid provides in certain situations. Lee will also talk about consumer direction in conjunction with Medicaid. Again, please understand that what you will learn in these modules are only generalities about the basics of Medicaid.

This module will help you be able to:

- Understand the concept of waivers.
- Learn about specific home and community-based services in your state.

Term Definitions

entitlement: Everyone who applies and qualifies can receive services.

homebound rule: A Medicare rule that states that people must be unable to leave home in order to receive homecare services.

(Previously home services were only offered by Medicare to people who were homebound.)

Medicaid Waivers

In this section of the module you will get to learn more about specific state waivers and what to remember about waivers in general. Understanding waivers in the Medicaid process can be very beneficial in getting services.

Waivers: Exceptions to the Rules

In addition to the state plan, states have waivers. Waiver services are provided *in addition to* the state plan services that cover basic and optional services discussed earlier.

Waivers provide exceptions to existing Medicaid rules and regulations that states typically have to follow. There are three kinds of waivers: Freedom of Choice Waivers, Research and Demonstration Waivers, and Home and Community-Based Services Waivers. Each is briefly explained below.

- *1915(b) Freedom of Choice Waivers:* States can limit a person's choice of provider. These waivers are in states that have mandatory managed care.
- *1115 Research and Demonstration Waivers:* States can try out innovative approaches that are "cost neutral."
- *1915 (c) Home and Community-Based Services Waivers:* States ask to "waive" rules around institutional placement so they can provide alternatives in the community.

Requirements That Can Be Waived

States can waive several requirements in a Home and Community-Based Waiver such as "Statewideness," Comparability, Cost Ceiling, and Entitlement.

"Statewideness": Waivers that can be granted to allow programs to serve people in some areas of a state and not all areas.

For example, Allan mentions that a state can do a home and community-based waiver only in Hartford, Connecticut, which would be perfectly legal. You can live in one area and be eligible for it, and live in another area and not be eligible.

Comparability: Waivers can target specific diagnostic groups and states can provide extra services to people in that group. For example:

- States can have an AIDS-HIV Waiver and a Children with Special Health Care Needs Waiver.
- Some states have as many as 12-14 waivers for different parts of the population, in different parts of the state.

Note: It is important to note there are no legal protections for people who could benefit from waiver services but who have a different diagnosis from the one defined in a waiver.

Remember, in regular Medicaid if you offer a service it *has to be available* to all comparable groups.

Cost Ceiling: Waivers can set an upper limit on how much can be spent for a service. Regular Medicaid does not permit cost ceilings.

Entitlement: Waivers can set a limit on how many individuals receive services. Waivers can have "Wait Lists" or waiting lists. Regular Medicaid does not permit waiting lists.

Important Waiver Features

Lee Bezanson explains several important things for you to remember about state waivers as you advocate for services. Each of these issues is reviewed below.

State Control

There's a ceiling on how much states can spend in waivers. Hence, they like to do waivers because they feel they have some control over the money spent. For example, if a state applies for a waiver, it would have to prove that the aggregate cost (combined cost for all of those who are eligible) of the waiver will be no more expensive than what it would have cost if those people were served in an institution. States feel more comfortable in expanding waivers rather than state plan services because they can control costs more.

No Duplicate Services -- State Plans vs. Waivers

States can choose to cover a service in their Medicaid state plan or take a service that was in their state plan and put it in a waiver. But what they can't do is duplicate services. Sometimes what states put in a waiver are additional benefits such as occupational therapy, physical therapy, and speech therapy...and keep it more restricted on the state plan (entitlement) side.

No Waiver Numbers Limitations

There used to be a limit on how many people could be served in a waiver. Now, however, that's not true. The limitations on how many people in waivers are now determined by two things:

1) How much money for matching funds the states have, and 2) whether or not they have the infrastructure in the local communities to support the people living there.

Institutionalization Alternatives

Waivers only serve people who are eligible to be served in an institution. People whose disability is not severe enough to qualify for a nursing home or other institution cannot qualify for Home and Community-Based Waiver services.

Money Flow

There are some important things to remember about Medicaid regarding money.

Medicaid is Not a Cash Assistance Program

Medicaid purchases services. It is not a cash assistance program.

Waivers Can Pay Family Members

Although Medicaid is not a cash assistance program, family members can be paid in waivers for being the caretaker or being a worker. The exception to this would be a parent of a child with a disability under 18 and a spouse of a person with disabilities.

Families and Individuals with Disabilities Can Direct Their Own Services

Families and individuals with disabilities can direct their own services and be in

charge of payments to workers. There are many different approaches that can be used to empower families and consumers to be able to make the choices in their own lives. Since the Supreme Court's Olmstead decision, people living in institutions have a right to say "I want out!" as long as treatment professionals agree with it.

Waivers Cannot Pay for Room and Board

Medicaid will only cover housing costs in an institutional setting like a nursing home or an ICF/MR. Instead, you need to persuade housing programs (for example through housing and urban development) to pay for these services.

Now that you better understand waivers, read Allan Bergman's biography and listen as Lee and Allan review these concepts.

Biography

Allan Bergman

Allan Bergman is President and Chief Executive Officer of the Brain Injury Association. He has served as Director of Governmental Affairs for the United Cerebral Palsy Association. Bergman headed a state association of home and community-based providers and directed two local HCBS organizations.

Play the video, Module 5 Part II, Section 1: "Medicaid Waivers" (7 minutes). After Section 1 is finished, proceed to the exercises below.

Application and Discussion

Questions for You

1. Do you know which of the three types of waivers your state has? (from Alan Bergman's discussion)
2. Can you list Home and Community-Based waivers that cover specific target groups in your state?
3. Do you have Wait Lists for waivers in your state? If yes, what do you know about them?

Questions for the State Medicaid Representative

Learn about your state Medicaid waivers. How many waivers are there for youth (under 18) and adults? Ask for a list of Home and Community-Based Services (1915c) Waivers in your state.

1. Who are the targeted groups for these Home and Community-Based Services Waivers? What are the specific requirements to qualify?
2. Are there waivers specifically designed for youth?
3. Do waivers target a specific geographic location or are they statewide?
4. Are the income and asset limits for waivers different from the general Medicaid program and are they different for youth than for adults?
5. What specific services are provided by each waiver?
6. Where do youth and adults apply for each specific waiver?
7. Are there Wait Lists for waivers?
8. Discuss the reasons that specific disability and specific age groups might have waivers while others do not. Do you know the history of how each waiver originated? What process is used to amend or change a waiver in your state?

Medicaid and Community Supports

In this final section, you will learn how state plan (basic and optional) services and waiver services can combine to provide many different kinds of supports needed by individuals with disabilities to live in the community. We will begin by talking about the importance of the community infrastructure and various supports Medicaid programs can buy. We will then explain Home Health and Personal Assistance Services (PAS) and how consumer direction can play an important role in the success of PAS.

Community Infrastructure

You will need to put together what you learned in Part I of this module with what you learned about waivers in Part II to see the “big picture” of how Medicaid is important to a comprehensive community infrastructure.

When we use the word “community” we mean *not in an institution*. The community is a home where a person lives, and the place where a person works, plays, goes to school, to church, or travels, etc. We need to recognize all the different parts of a community in order to build the supports people with disabilities need to live in it.

Medicaid is a funding source that can be used to build supports for people who are eligible for it. If you start with the concept of “community” as a place where people live their lives – and the idea that people with disabilities have particular needs – you can fill in the gaps with individualized supports that allow people to live in as normal a way as possible.

Supports

Here are some examples of supports Medicaid programs can buy. These services may be available through the state plan (as either basic or optional services) or through a waiver. Services that are traditionally medical services are available through the state plan, while those services that are considered “wraparound” are offered through waivers.

- Respite
- Caregiver training
- Vehicle modification
- Home nursing
- Extra health care and therapy benefits
- Day programs or supported employment programs (SEP)
- Summer camp
- Case management
- Communications aids
- Personal assistance
- Home modifications
- Adaptive equipment
- Emergency Home Response
- Dental care
- Crisis supports
- A Medicaid card
- Supported employment

Home Health Services

Home health services are a basic (mandatory) service in the state plan. A state may offer very limited services in the state plan but offer additional home health services to a specific group through a waiver. In home health services, a registered nurse may come to a person’s home to provide skilled nursing care or a home health aide may come to provide routine help with bathing or monitoring medications. These services are always provided in the home.

Personal Assistance Services (PAS)

Personal assistance services can be an optional state plan service or a waiver service. PAS have been broadened in recent years so that under Medicaid they can be offered in the home, outside the home, in the school, and in the workplace. Personal assistance services (also called personal care) may provide a person with a disability help with bathing, dressing, eating or with meal preparation, shopping or house cleaning.

Consumer Direction

Consumer direction means that individuals with disabilities can direct their own services. Consumer direction can play an important role in personal assistance services.

Historically, consumer-directed services were only available to people who could direct their own services. It is now being expanded to families who can use it for children and people with cognitive disabilities. Now many more individuals can enjoy consumer direction.

This is an important step forward for Medicaid, and increasingly you will see Medicaid programs offering self-direction and consumer-directed services.

In order to find out how to obtain the kinds of supports Medicaid can provide, you must become familiar with your own state plan. This task sounds tedious and not very exciting, but if you know what to ask for, it can pay off in a big way for your advocacy.

Play the video, Module 5 Part II, Section 2: “Home and Community Services” (3 minutes). After the section is finished, proceed to the exercises below.

Application and Discussion

Questions for You

1. Read the list of community supports and see if you know someone who receives any of these services from Medicaid. Do you know if the service is “state plan” or “waiver?” How can you tell? Why is it important to know the difference?
2. Do you know anyone who receives personal assistance services (PAS)? Are PAS services “consumer directed”? If yes, what does that mean for the person receiving PAS?

Questions for the Medicaid State Representative

1. Does the state have options for consumers to direct their own services? Which services can have consumer direction? Is consumer direction different for youth than for adults?
2. If consumer direction is an option, does the state require use of Intermediate Service Organizations?
3. How do fiscal intermediary services work (also called Intermediate Service Organizations)? How can youth and families best utilize their services?
4. Review the Home Health section of the state plan. How can Home Health services be coordinated with other services provided in waivers?

5. Review the Personal Care Services (also known as Personal Assistance Services or PAS) offered in the state plan and in waivers. What is the difference between Personal Care State Plan services and Personal Care Waiver services? Are they targeted to different groups? Are the amounts and duration of state plan services different from waiver services?
6. Discuss the reasons that a person might need to access state plan services and waiver services at the same time? Is this a duplication?

Beyond Medicaid Waivers—What’s Next?

In Part II of this module you were able to learn about Medicaid waivers or services that are provided *in addition to* the state plan services. You were able to speak with a state Medicaid representative and ask questions. As you can see, waivers are important to know about as you are developing advocacy plans.

Next, in the summary section, you will be able to tie together all of the information you have learned about in each of the modules.

For More Information

Transition resources available online:

Mapping Your Dream Series – Home Living

<http://www.pacer.org/tatra/MYD-HomeLiving.htm>

Adolescent Autonomy Checklist, Developed by the Youth in Transition Project,
University of Washington Division of Adolescent Medicine

http://depts.washington.edu/healthtr/checklist_print.doc

The Illinois Division of Specialized Care for Children’s List of Transition Resources

<http://internet.dsc.uic.edu/dsccroot/parents/transition.asp>

The Association of University Centers on Disabilities (AUCD) has a website that gives basic to advanced information on Medicaid

http://www.aucd.org/aucd_medicaid.htm

<http://www.responsetrack.net/Ink/aucd/?10N2004BHDP>

The Arc of the United States has a website that provides a 2-page fact sheet on Medicaid programs offered by each of the 50 states and D.C.

[Http://www.thearc.org/medicaid/](http://www.thearc.org/medicaid/)

Medicaid served more than 7 million people with disabilities in the U.S. and is the primary public source of funding for health and long-term services and supports for people with disabilities of all ages.

[Http://www.responsetrack.net/Ink/thearc3/?10N2O04BHDP](http://www.responsetrack.net/Ink/thearc3/?10N2O04BHDP)

Olmstead and Community

Summary: Tying It All Together

Workbook

Summary

A Final Remark

“Laws can embody standard; governments can enforce laws—but the final task is not a task for government. It is a task for each and every one of us. Every time we turn our head the other way when we see the law flouted—when we tolerate what we know to be wrong—when we close our eyes and ears to the corrupt because we are too busy, or too frightened—when we fail to speak up and speak out—we strike a blow against freedom and decency and justice.”

~Robert F. Kennedy, Attorney General, 1961

These modules have provided a good foundation and a basic framework for carrying out your goals of advocacy. We would suggest that you review the modules periodically to remind yourself of the valuable and important information that successful advocates were willing to share.

This summary and culminating activity will help to tie all of the information together so that you may have good direction in your advocacy. Read each of the module summaries to refresh your memory on what you learned before you proceed to the exercises.

Module 1: Disability Policy Framework

In *Module 1: Disability Policy Framework*, you wrote down a main advocacy goal to help you apply the principles you would learn. Bobby Silverstein then set the stage and provided us with the map or the framework from which we should build our advocacy plans. He also gave us a checklist to assist us in developing our goals and strategies. The methods of administration are a necessary part of implementation, and the planning model provides important and effective steps to help us in developing and implementing our advocacy plans. (*See Module 1 for the complete checklist and steps of the planning model.*)

Old Paradigm vs. New Paradigm

We learned about the old paradigm and contrasted it with the new paradigm. Bobby Silverstein also discussed the core precept, which is that disability is a natural part of the human experience and the approach should be to fix the environment; not the individual. Bobby talked about the importance of understanding history and the mind set of people so that we can address these issues and ensure that history does not repeat itself.

Four Goals of Disability Policy

We also learned the four goals of disability policy that we should address when being advocates, which are: Equality of Opportunity, Full Participation, Independent Living, and Economic Self-Sufficiency.

Equality of Opportunity

In the Equality of Opportunity Goal, we need to make sure that individualization is addressed. We need to remind lawmakers that every individual has a right to experience what everyone else experiences, and make sure we don't get into the habit of using jargon or words that make people defensive such as "reasonable accommodation" or "program accessibility." Instead, voice the fact that everyone should have an effective and meaningful opportunity to participate, and make sure that inclusion and integration are addressed. A person should not have to be segregated or separated in order to get a public benefit.

Full Participation

In Goal Two: Full Participation, we should make sure that the individual is empowered with information to make the best choice for themselves. They should be able to be involved in making decisions at the policy level.

Independent Living

Goal Three: Independent Living states that we need to make sure the system supports independent living. Does it provide personal assistance services, assistive technology and cash assistance?

Economic Self-Sufficiency

The fourth goal, Economic Self-Sufficiency, addresses support in infrastructure such as education, employment, cash assistance, and work incentives.

Planning Model

The planning model lists four important steps to take in developing and taking action on your advocacy plan: 1) Take stock, 2) Set goals, 3) Develop strategies and take action, and 4) Document progress.

Appendix A explains examples of major federal legislation that contain the disability policy framework. If you are interested in the methods of administration that Bobby talks about or monitoring and enforcement and procedural safeguards as well as financing service delivery, read Appendix B: Methods of Administration--Discussion.

Module 2-IL: Olmstead for 'Newbies'

The U.S. Supreme Court decision, known as *Olmstead vs. L.C.* in Module 2, shows how we can effectively use the goals of the disability policy or the framework that Bobby talked about. Lois Curtis and Elaine Wilson became victorious and were able to live in the community instead of an institution. We learned about the conditions that led to the Olmstead decision and learned how the Olmstead decision can affect each of our own states and living situations.

Module 3: Consumer Direction: Taking Control

Module 3: Consumer Direction: Taking Control, helped us understand the important principles of consumer direction, self-determination, and consumer control. In each of these concepts, persons with disabilities can take control of what happens in their lives by being involved in decision-making. Consumer-directed approaches were compared with professionally-managed services and assisted us in understanding the supports available to help consumers who want to direct their own services.

Appendix C: Issues for Advocacy in Consumer Direction *explains the issues and concerns that are important to understand if we become involved in advocating for increased consumer direction; such as stereotypes and assumptions about the consumer's age, controversy about paying family members, assuring quality in home health, and quality performance of skilled nursing tasks.*

Module 4-IL: Getting People Out of Nursing Homes and Other Institutions

We learned important things about either helping ourselves or someone we care about get out or stay out of nursing homes. *Module 4: Getting People Out of Nursing Homes and Other Institutions* helped us understand the infrastructure or the supports necessary (i.e., housing, benefits, community access, and PAS) in the community so people with disabilities can live independently outside of institutions. Mike Oxford talks about these supports and gives us ideas on how to obtain them. We read about the barriers such as changes, responsibilities, and risks that may prevent people from leaving nursing homes and we listened to Bob Kafka and Mike Oxford discuss strategies to overcome the barriers.

Module 5: Medicaid Framework

Finally in *Module 5: Medicaid Framework*, we read about and listened to Lee Bezanson and Allan Bergman explain the basics of Medicaid and the state waivers that can be obtained through Medicaid to obtain services and supports to help people live independently in the community.

We understand your advocacy goal is very important to you and we want you to be able to have a clear plan that includes actions to be taken. To help you do this, answer the questions in the summary exercises.

Summary Application

1. What is your main advocacy goal? (Refer to Module 1, page 11 for an example.)
2. In Module 1 we talked about four steps in developing and implementing a plan successfully (pages 10-13). Also in Module 1, Bobby provided a checklist of questions we should ask about our own issue of advocacy (page 9). Using these two resources for developing and measuring the advocacy plan, answer the following questions:

- a. For your advocacy goal, take stock—review the situation. Find out what has led to the problem or issue. Identify actions that may have been taken previously and what the results were. Bobby Silverstein recommends taking time to “understand the history.”

This is the background of the problem I have selected for my advocacy plan:

- b. Set goals—identify a specific and measurable outcome that you would like to see happen. These are smaller steps that will lead to the accomplishment of your main advocacy goal. Specify goals that are consistent with the core precept (disability is a natural part of human experience; and fix the environment not the person).

The more specific the goal, the easier it will be to measure progress. A broad, long-term goal can be broken into smaller steps to better understand and illustrate the planning model.

These are the specific goals of my advocacy plan:

- c. Develop strategies and take action—decide what action to take. Identify the approach you will use to solve the problem and take action. Develop strategies that are consistent with the Four Goals of Disability Policy. These are my strategies:

Now using the information that you learned from Modules 2-5, answer the questions based on your advocacy plan:

3. What principles did you learn from the Olmstead decision that will help you be a better advocate?
4. How can principles of consumer direction and self-determination help to make a smoother transition for a person moving into the community? How can these principles help you in your advocacy plan?
5. What kinds of infrastructure supports do you need to have set up in the community? What obstacles or barriers do you foresee that you or an individual with a disability may need to address and overcome?

6. What Medicaid services and supports would be beneficial and effective in your advocacy plan? Would basic services be sufficient or would state waivers be more helpful? What is your plan of action for these supports?

Now that you have been through all of the modules and have your advocacy plan developed and strategies in place, the next step is to take action and follow your plan so that you can perform the last step of the planning model: document progress. Remember this is a crucial part of implementing your plan. Are your methods effective?

7. Document progress – Record the results of the actions that were taken. By reviewing progress, you are again “taking stock” of the situation to decide if the actions have been effective – and if progress has not been made, repeat the steps of the planning cycle with new, improved strategies until the goal is completed.

This is the progress that has been made:

These are the new goals and strategies:

As you take action in your advocacy goal, we encourage you to continually review the principles within each of the modules to remind yourself of important concepts and actions. Effective advocacy takes time. Be patient, but never give up.

“Keep your face to the sunshine and you cannot see the shadow.” Attributed to Helen Keller.

Appendix A: The ADA and Other Examples of Major Federal Legislation that Contain the Disability Policy Framework

The ADA (Americans with Disabilities Act), as mentioned in *Module 1: Disability Policy Framework*, is an example of a major piece of legislation that reflects the disability policy framework.

The ADA is a federal civil rights law designed to prevent discrimination and enable individuals with disabilities to participate fully in all aspects of society. The ADA was passed by Congress and signed by the President in July 1990.

<http://www.usdoj.gov/crt/ada/publicat.htm#Anchor-14210>

The ADA recognizes the history of treatment of people with disabilities

The first part, the *Findings* section, states the reasons that Congress passed the law. This section describes problems that the law is intended to address. For example:

- “Historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.”

It also states:

- “Individuals with disabilities have been...subjected to a history of purposeful unequal treatment and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society.”

The ADA states the four goals of disability policy

The goals of the law are stated as follows:

“the Nation's proper goals regarding individuals with disabilities are to assure

- equality of opportunity
- full participation
- independent living, and
- economic self-sufficiency for such individuals.”

The ADA reflects the new paradigm that disability is a natural part of human experience, and the solution is to fix the environment, not the person

The law has five major sections that address 1) employment, 2) state and local government services, including public schools and public transportation, 3) public accommodations and services operated by private entities, 4) telecommunications, and 5) miscellaneous provisions.

Throughout the law, the focus is on how to “fix the environment” to eliminate discrimination and level the playing field to allow people with disabilities to participate in and contribute to society. The ADA relies on the concept of “reasonable accommodation” under the employment provisions (Title I), which is a legal term for fixing the environment.

To be protected by the ADA, a person must be a qualified person with a disability. For example, under the employment section, « a qualified employee or applicant with a disability is an individual who, with or without reasonable accommodation, can perform the essential functions of the job » in question. Reasonable accommodation may include, but is not limited to:

- Making existing facilities used by employees readily accessible to and usable by persons with disabilities.
- Job restructuring, modifying work schedules, reassignment to a vacant position.
- Acquiring or modifying equipment or devices, adjusting modifying examinations, training materials, or policies, and providing qualified readers or interpreters.

To read the full text of the ADA, visit the following website:

<http://www.access-board.gov/about/ADA%20Text.htm>

Other Examples of Major Federal Legislation

IDEA – Individuals with Disabilities Education Act of 1997

First enacted in 1975, this landmark legislation was needed to assure that students with disabilities receive free appropriate public education (FAPE) and the related services and support they need to achieve their educational goals. IDEA was created to help states and school districts meet their legal obligations to educate children with disabilities and to pay part of the extra expenses of doing so. Read it at:

<http://www.ed.gov/offices/OSERS/Policy/IDEA/>

Rehabilitation Act of 1973 (amended in 1998)

Federal legislation that authorizes the formula grant programs of vocational rehabilitation, supported employment, independent living, and client assistance. It also authorizes a variety of training and service discretionary grants administered by the

Rehabilitation Services Administration.

The Act authorizes research activities that are administered by the National Institute on Disability and Rehabilitation Research and the work of the National Council on Disability. The Act also includes a variety of provisions focused on rights, advocacy, and protections for individuals with disabilities.

<http://www.ed.gov/offices/OSERS/RSA/Policy/Legislation/narrative.html>

Developmental Disabilities Assistance and Bill of Rights Act of 2000

A federal law that authorizes four programs: Developmental Disabilities Council State Grants, Protection and Advocacy Systems, University Centers for Excellence in Developmental Disabilities Education, Research and Service, and Projects of National Significance, all of which are programs aimed at assisting people with developmental disabilities.

<http://www.acf.dhhs.gov/programs/add/DD-ACT2.htm>

Technology Act of 1998

A federal law that affirms that technology is a valuable tool that can be used to improve the lives of Americans with disabilities. The law aims to increase access to, availability of, and funding for assistive technology through state efforts and national initiatives. All states are eligible to receive 10 years of federal funding for their state assistive technology program, and states that have completed 10 years may receive 3 additional years of federal funding.

<http://www.ncddr.org/relativeact/statetech/ata98.html>

Appendix B: **Methods of Administration--Discussion**

On the tape in *Module 1: Goals of Disability Policy*, Bobby Silverstein described the four goals of disability policy. He wants you to understand the goals, but says that the goals are “only half” of what is important. He uses the phrase “methods of administration” to refer to components of laws and procedures that affect how a policy is carried out or implemented. Bobby implies that what really matters is not only what is written down, but how people act on those written words. Do these laws improve the lives of people with disabilities? That is the important question.

Below are three examples of methods of administration and how they may affect an individual’s services. You will see examples of Checklist questions to determine if these components are present in a policy or program.

Monitoring and Enforcement by Government Agencies

Laws don’t mean much without anyone to enforce them. If there are no highway patrol officers to enforce highway speed limits, do you think most people would obey them? Disability laws must be enforced just like any other laws. To be effective, laws must have people in outside agencies watching for compliance and taking legal action if they are not followed.

Checklist question: What agencies are charged with monitoring and enforcing the policy?

Procedural Safeguards for Individuals, Their Families and Representatives

This means you can appeal decisions that you don’t like. You don’t have to settle for what a service worker says you can or cannot get. Appeal mechanisms are “procedural safeguards” and allow you to ask for other persons to review the decisions that were made about you or your services.

Checklist question: Does the program have a system for appealing decisions that the consumer or family member or representative does not like?

Financing Service Delivery

Follow the money! Traditional financing approaches often favor existing programs or institutions. The financing of services has a big impact on whether individuals have flexibility and choices that meet their needs. How are the services paid for? Does the program allow individuals with disabilities to decide what services are purchased for them?

Checklist question: Does the system of financing maintain existing programs or institutions? Does it allow for flexible service delivery?

Methods of Administration - Bobby Silverstein’s Checklist for Administration

1. State and local plans.
2. Monitoring and enforcement by government agencies.

3. Personnel development.
4. Procedural safeguards for individuals, their families, and representatives.
5. Accountability for results (outcome measures).
6. Representation at individual and systems levels.
7. Single line of responsibility, coordination, and linkages among agencies.
8. Service coordination (case management).
9. Financing service delivery.
10. Privacy, confidentiality, access to records, and informed consent.
11. Responsiveness to cultural diversity.
12. Financial management and reporting.
13. Support for improving program quality (system change initiatives, research).

Appendix C: **Issues for Advocacy in Consumer Direction**

Several issues are important to understand if you become involved in advocacy for increased consumer-directed services in your community. The issues discussed are:

- 1) Stereotypes or assumptions about consumer direction related to the age of the consumer.
- 2) Controversy around paying family members as providers.
- 3) Assuring quality in home-based services.
- 4) Performance of skilled nursing tasks.

Each issue discussion includes references to recent research to illuminate the current state of knowledge about these important consumer direction issues.¹

Assumptions about Consumer Direction Related to the Age of the Consumer

Some people may question whether consumer direction is appropriate and desired by older persons. The preferences and experiences of those over age 65 may seem to differ in important ways from those of younger persons with disabilities. Older persons may be accustomed to services arranged by case managers and delivered by medically oriented home care agencies.

The elderly may have more unstable medical conditions and thus may need more professional monitoring at home than is true for younger persons with disabilities. For elderly persons, the focus of support services has been to maintain current levels of functioning at home and to slow what is seen as inevitable decline. In contrast, younger persons with disabilities tend to view home-based services not as an end in themselves but as a means to a better life. For them, quality of life is defined not solely in terms of maintenance at home but of education, employment, recreation, and other activity outside the home. Younger persons with disabilities are seen as more grounded in “independent living” ideals and as having stronger preferences for directing their own lives.

Research shows that consumer direction is appropriate and desired by persons across age and functional abilities:

- Older persons are somewhat less enthusiastic about the benefits of self-direction, their expectations and experiences are similar to those of their younger counterparts.²
- The preference for self-direction among older persons is similar to younger persons when choices involve daily living, personal services, and home settings. Like others, they prefer to have a say in what is done, when, and how.³
- Older recipients may need more outside support in getting started and making consumer direction work.⁴
- Older persons are more likely to prefer hiring family members as support workers.⁵

Controversy Around Family Members as Providers

Federal Medicaid regulations prohibit federal payment to “legally responsible” family members (such as spouses or parents of minors). Some states will allow certain family members to be paid with other public (non-Medicaid) funds. Advocates of hiring family members argue that consumers must recruit their own workers and should not be limited in whom they may hire; in a tight labor market consumers need maximum latitude to recruit help. From a practical standpoint, family members represent a large pool of helpers for persons with disabilities.

Using public funds to pay family members for services to their relatives is a controversial issue. Taking care of family members is generally seen as fulfilling a moral duty. Also, critics worry that public payment weakens the moral bonds that support family commitments. Critics (often state officials) also suggest that the opportunity is great for fraud and abuse by families, and that paying family members would require more administrative monitoring, thus would increase costs. Critics worry that costs will explode if the availability of public payment persuades large numbers of family members, now providing services out of moral duty, to demand payment instead.

Debate about paying family members is further complicated by the argument from some disability advocates that family members should be the last choice in hiring, since familial ties complicate what should be an employer-employee relationship between consumers and workers.

While there is relatively little research on payments to family members, the following studies give some interesting information:

- In one study, about one in five paid family providers had not been providing unpaid services to the recipient prior to hiring, so the pool of available help expanded as a result of allowing payment to families.⁶
- The same study found that certain outcomes (including a feeling of safety and choice) are more positive for consumers when the provider is a family member.⁷
- The Cash and Counseling Demonstration (where consumers select their workers) found little fraud and abuse in either family or non-family provider arrangements.⁸
- Few if any systematic data exist to compare abuse of consumers or program funds in agency care, services by consumer-hired non-relatives, and paid family arrangements.⁹

Deciding What is Quality

Quality can mean many things. From a consumer perspective, quality is fairly simple. If you are the one who receives personal assistance, quality means: Does the worker do what you want, when you want it, and how you like it done? Is the worker respectful to you? You don't need a professional licensing agency to tell you what is quality.

Advocates of consumer direction argue that uniform professional standards have only limited relevance to how people judge the quality of their support services and relationships with their workers. In this view, professional oversight may be unnecessary

for services that are intimate and personal and only minimally medical or technical. Where personal services in the home are involved, values and preferences will vary about what are essentially quality-of-life issues, such as what is appropriate, adequate, comfortable, and secure. In this case, adequate performance can reasonably be judged by the person to whom services are provided.

A few studies have looked at quality in home-based services. A small number of studies suggest that the actual risks to consumers associated with self-direction seem no greater than those with agency-based services.

- A study of elderly Medicaid recipients in three states found a strong association between participation in a consumer-choice program and recipients' satisfaction with personal assistance services.¹⁰
- A small study of younger recipients of consumer-directed services in Virginia found that they reported higher satisfaction and greater work productivity than those receiving agency or informal services.¹¹
- In a federally funded study of recipients assigned to agency-delivered versus consumer-directed services in California, service outcomes for the self-directing group were no different from those of agency recipients on measures of safety and unmet needs and more positive on measures of service satisfaction and quality of life.¹²
- The same study found that home care agency workers received less service training than expected, while consumer-hired workers received more than predicted, although from diverse and unplanned sources (such as from a family physician or a home health nurse).¹³

Performance of Skilled Nursing Tasks

A central assumption of consumer direction is that most personal assistance is not medical. Yet medically related procedures such as assistance with medications, injections, catheters, and ventilators are part of daily life for many persons with disabilities. Assuring the adequate oversight of medically related services delivered at home remains a challenge. States have adopted nursing practice laws that define nursing tasks and prohibit non-licensed persons from performing them.¹⁴

Although consumer-directed services reject the medical model, state laws and regulations about the performance of "skilled nursing tasks" make avoiding a medical model difficult. Federal Medicaid policy does not dictate who must perform skilled nursing tasks, only that such tasks must be performed in compliance with applicable state laws. But state laws and regulations often dictate that such tasks be performed by or closely supervised by a licensed nurse--thereby creating barriers to consumer direction. Liability concerns sometimes also stand in the way of promoting consumer-directed service models.

A 1999 HCFA State Medicaid Manual transmittal specifically states:

"Services such as those delegated by nurses or physicians to personal care attendants may be provided so long as the delegation is in keeping with state law or regulation and the services fit within the personal care

services benefit covered under a state's plan. Services such as assistance with medications would be allowed if they are permissible in states' Nurse Practice Acts, although states need to ensure that the personal care assistant is properly trained to provide medication administration and/or management.”

Most states restrict performance of medical or "paramedical" tasks to licensed medical professionals, although most physician and nurse licensing laws do permit individuals to be trained to perform skilled services for themselves or for close family members. Federal Medicaid law references state licensing laws by requiring that state Medicaid plans comply with all "applicable" state and local statutes.

Under the Nurse Practice Acts in most states, tasks such as catheterization, injections, and administering medications are considered invasive procedures, which may be performed only by paid personnel who are registered nurses or persons supervised by registered nurses.

In a 1997 Medicaid conference they identified two alternative approaches that several states use in addressing non-licensed persons performing nursing tasks. The two models are: DELEGATION and EXEMPTION.

Delegation

Registered nurses (RNs) may delegate “nursing” tasks to individuals they train and supervise. Accountability for delegated tasks remains with the RN. Some Nurse Practice Acts hold nurses strictly accountable for any negative outcomes of tasks performed by their delegates. If the worker to whom a task was delegated negligently harms the consumer, the RN would be liable only if it were established that his or her assessment, training, supervision, or other aspect of the delegating process were performed negligently. Most Nurse Practice Acts do not differentiate between delegation in an inpatient setting, such as a hospital or nursing homes (as contrasted with nurse delegation in a home care setting).

Exemption

The exemption alternative provides a way to deal with liability concerns. The primary difference between specific delegation and exemption is where the authority and responsibility lie. In an exemption approach, it is the implicit right of the person needing a service to manage provision of a service, as he or she prefers, as long as the provider of service falls within the exempt category. Nurses are not held responsible for provision of the service, but they may continue to play an important role in educating the provider and the consumer of the service--as well as, in some instances, monitoring the service over time. Several states have dealt with the delegation issue by providing specific "exemptions" in their Nurse Practice Acts for consumer-hired personal attendants in Medicaid funded programs. (Most, if not all, states exempt family members.) This approach not only protects nurses, who may assist in training consumer-hired aides without assuming liability for the aides' subsequent actions; it also protects the state against liability for any harm that might be caused by consumer-directed aides.

Group Activity

Select one of the four Issues for Advocacy discussed in this appendix and discuss the questions below on your selected topic.

1. Stereotypes about Consumer Direction and Age of the Consumer

Do you know an elderly person who needs personal assistance at home? What are your assumptions about that person's desire and ability to be self-directed? Does that person have family member(s) involved with caregiving? Discuss what you think are differences in the desires and needs of elderly persons compared with younger adults who need personal assistance.

2. Paying Family Members

Do you think that the ability to pay a family member would encourage more people to become personal attendants? What do you think about public officials' concerns that if family members were paid, many who now provide support at no cost would expect to be paid, and the government costs for care would "skyrocket"? Is this a realistic concern?

3. Assuring Quality in Consumer-Directed Services

Do you know of instances where individuals with disabilities were abused or neglected by their paid caregivers? Did this occur at home or in a nursing facility? Discuss the research finding that "home care agency workers received less service training than expected, while consumer-hired workers received more than predicted, although from diverse and unplanned sources."

4. Performance of Skilled Nursing Tasks

Discuss specific examples of routine services that individuals with disabilities might require that must be performed by a licensed nurse. What are the risks to the person with the disability in having someone without the proper skill perform the task? Does a person with disability have the right to take the risk for him/herself?

Research to see if your state allows Delegation or uses Exemption for individuals with disabilities to receive services covered by the Nurse Practices Act. What are the implications of either approach for the individual who needs the services?

NOTES

¹ The first three “issues for advocacy” are discussed at greater length in A.E. Benjamin (2001) “Consumer directed services at home: A new model for persons with disabilities,” *Health Affairs*: 20:6. The fourth issue on nursing tasks is discussed in Smith, G. et. al. (2000), *A Medicaid Primer*. George Washington University: Center for Health Policy Research.

² Simon-Rusinowitz, L., et. al. (1997) “Determining consumer preferences for a cash option: Arkansas survey results,” *Health Care Financing Review*: 73-96.

³ Miller, N. (1997) “Patient-centered long term care,” *Health care financing review*: 1-10 and Eustis, N.N. and Fischer, L.R. (1992). “Common needs, different solutions? Younger and older homecare clients,” *Generations*: 17-23.

⁴ Benjamin, A.E. and Matthias, R.E. (2001) “Age, consumer direction and outcomes of supportive services at home,” *Gerontologist*: 1-11.

⁵ Benjamin, A.E. and Matthias, R.E. (2001) “Age, consumer direction and outcomes.”

⁶ Benjamin, A.E., et. al. (1999) “Consumer direction and in-home services: Recipient perspectives on family and non-family service provision,” *Journal of rehabilitation administration*: 233-247; and Benjamin, A.E., Matthias, R.E., and Franke, T.M. (2000) “Comparing consumer-directed and agency models for providing supportive services at home.” *Health Services Research*: 351-366.

⁷ Benjamin, A.E. et. al. (1991). “Consumer direction and in-home services.”

⁸ Mahoney, K.J., Simone, K., and Simon-Rusinowitz, L. (2000). “Early lessons from the cash and counseling demonstration and evaluation,” *Generations*: 41-46.

⁹ Blaser, C.J. (1998) “The case against paid family caregivers: Ethical and practical issues,” *Generations*: 65-69.

¹⁰ Doty, P., Kasper, J., and Litvak, S. (1996) “Consumer-directed models of personal care: Lessons from Medicaid,” *Milbank Quarterly* 74: 3: 377-409.

¹¹ Beatty, P.W. (1998) “Personal assistance for people with physical disabilities: Consumer-direction and satisfaction with services,” *Archives of physical medicine and rehabilitation*: 674-677.

¹² Benjamin, A.E., et. al. “Comparing consumer directed and agency models.”

¹³ Benjamin, A.E., et. al. “Comparing consumer directed and agency models.”

¹⁴Smith, G. O’Keeffe, J., Carpenter, L., Doty, P., Kennedy, G., Burwell, B., Mollica, R. and Williams, L. (2000) *A Medicaid Primer*. George Washington University, Center for Health Policy Research.