

Introductory Script

Today we will be focusing on the evolution of human rights for persons with developmental disabilities. We will also cover this agency's (or facility's) policies on human rights, information about this agency's human rights and behavior management committees and what your role is in protecting individual rights.

Please take a moment to read over the **Table of Contents** for this module and familiarize yourself with the topics that we will discuss today.

Next we have the introduction that is written by self advocates. Please take a moment to read this introduction and then we will discuss human rights from the self-advocates' perspective.

You may want to ask trainees to define "self-advocate."

Materials needed for this module include:

- Sample of Agency Behavior Plan with confidential information removed.
- Note cards (5 for each participant) to be used in activity "Losing an Important Thing in your Life"
- Example of agency Client Rights Statement specific to their work site. (Be sure to black out personal information, if any). Discuss this with trainees, touching on your agency's policies.

Evolution of Rights

You would think that rights, such as those in the Constitution, would be for everybody; however, until fairly recently, individuals with disabilities were considered to have no rights.

It wasn't until 1971 that the United Nations issued its "Declaration on the Rights of the Mentally Retarded Persons."

This declaration can be found at:

http://www.un.org/esa/socdev/enable/disdevelopmental.htm#_Toc35445324

- 1971 is not that long ago.
- The declaration helped mobilize advocacy groups and brought about legislative changes and legal actions. This resulted in highlighting rights issues for individuals with disabilities.
- These same rights are now available to all individuals. It is our responsibility to make sure these rights are protected for each individual we support. This is especially true when it comes to providing an environment that is free from abuse and neglect. We will discuss those topics in Module 3.

Advocacy

Over the years there have been important court decisions that have helped ensure the rights of people with developmental disabilities. We will discuss some of those later today. However, advocacy groups and individuals, such as yourself, are needed to assist and support individuals in protecting those rights.

Ask DSPs for ways that they can act as advocates for the people they support. Presenter may record them on a flip chart or wipe-off board.

Responses may include the following:

- Listening carefully to what another person says, and speaking up for the person's needs
- Working hard to know what someone really wants or needs
- Allowing the individual to take risks that are in accordance with their ISP.
- Allowing opportunities for choice whenever possible.

The Right to Dignity and Respect through Positive Interactions

Presenter should discuss some interactions that might be considered a restriction of individual rights.

For example: A DSP tells a person, "If you don't clean your room, you can't go shopping today."

Discuss how this is not proper because restriction of freedom of movement must be a part of the service plan. The DSP cannot restrict someone from accessing the community unless it is in the Service Plan!

Then discuss how saying "If you clean your room now we can go shopping earlier!" is a **positive interaction** attempting to reach the same end.

Sample Empowerment Worksheet

Discuss how to rephrase each statement to reflect a positive interaction.

Discuss how giving acceptable options to some of the cases provides structure for responses.

For example, using a question form for statement number one "Do you want to go take a bath?" might not produce a successful response, as one can just say "No!"

The question "Do you want to take a bath now or after your TV show is finished?" provides more structure but allows choice as well as a positive tone.

Discuss how each statement can be made as a positive interaction empowering the individual.

The Right to Intimacy

We've talked about some of the Constitutional rights of people with developmental disabilities. We're going to discuss some of these rights that you may deal with on a day-to-day basis as a DSP.

We will be discussing such things as:

- **The Right to Intimacy**
- **The Right to Privacy**
- **Free access to the Telephone**
- **The Right to Freedom of Movement**
- **The Right to Free Association**

Cultural Competency

In your role as a DSP, you may interact with people from various backgrounds and cultures. Therefore, it is important to understand how culture can affect behavior. That is, cultural differences are sometimes interpreted as intellectual disadvantages.

Sometimes there are different perceptions about families and how involved they become in the support of the individual. Cultures vary widely in this respect. A person of one culture may expect, as a matter of course, that his/her whole family (parents, siblings, children, cousins, aunts, uncles, etc.) will be involved with the service process. An individual of another culture may be humiliated by the involvement of just one other family member.

Sometimes people of various cultures may see 'seeking help' for an individual as a sign of weakness because the family considers themselves as responsible for the care of all its members. If the family is seen as responsible for the care of all its members, then seeking help from agencies is seen as dishonorable and injurious to family pride.

For example, within some cultures, disability may be seen as punishment by God, and therefore a source of shame and guilt. This may lead to resignation and overprotection of the individual. With little expected of him or her. Persons with disabilities may be treated as children, and/or shielded from the public. Some cultures may try to treat the person at home until it becomes a crisis.

The Choice Making Process and Personal Freedoms

It is our human right to make our own decisions. People with intellectual disabilities have often been denied the opportunity to choose some things like what to eat, what to do, and who to spend time with. **Without experience people do not know how to make a decision.**

Most of us take choice-making for granted. We make choices every day. Many of the "choices" that people with intellectual disabilities are offered would not meet most people's definition of choice. For example, for a person who wants a job, a choice of which sheltered workshop station to sit at is not a **real** choice.

Sometimes a person may have very limited communication or very limited experience from which to make a choice. As a DSP, you may be called upon to help support decision making.

Guardianship

Sometimes an individual with Developmental Disabilities may also have a guardian. The guardian has the ultimate responsibility for ensuring an individual's rights are protected. An individual may have a guardian appointed by the court if s/he is unable to make or communicate decisions regarding his/her own welfare.

Almost anyone can serve as an individual's guardian. If an individual has no interested family or friend(s), the Office of State Guardian may be appointed as guardian.

Behavior Management and Human Rights Committees

The Behavior Management and Human Rights Committees also serve important functions within our agency.

Discuss agency specific topics such as:

- **How often each committee meets**
- **How many individuals serve on each committee**
- **Who serves on each committee**
- **Types of issues that get brought to each committee.**

Point out that even though they may not directly appear at the HRC, DSPs have an important role as the first-line staff who knows an individual best. Their input is vital!

The BMC is responsible for reviewing the technical aspects of behavior plans. The HRC is responsible for ensuring that no rights are being violated.

Behavior Treatment Plan

Distribute a sample of a Behavior Treatment Plan (BTP) for the trainees to insert in their notebooks. Make sure all confidential information is removed or blacked out.

Spend a few minutes going over it. Discuss with trainees things that may be discussed by the Human Rights Committee such as ensuring that:

- The behavior treatment plan does not unduly restrict a person's rights and **if** the rights are restricted, what is the plan to potentially regain rights.
- All staff have clear, specific instructions on how to respond when specific behaviors arise.

ACTIVITY – LOSING AN IMPORTANT THING IN YOUR LIFE

(Presenter will need to have five note cards for each trainee for this activity)

Instructions: *Write down the five most important things in your life. This might be a person, a belief, an object, etc.*

“Record each one on a separate index card.”

“When finished, look at your cards.”

(The Presenter then takes one index card and throws the card on the floor in front of the card's 'owner'. This can be done in 'round robin' style until only one or two cards are left for each person.)

Trainees are asked to record their feelings on a blank sheet of paper after having these important things taken away from them.

- *How did this exercise make you feel? Angry? Frustrated? Frightened? Like a traitor?*
- *Feelings like you experienced are entirely normal any time you are forced to give up someone or something of value to you. This sense of loss is also felt by persons with developmental disabilities in a variety of ways. You will never know what or who is important to an individual until you get to know him/her.*

Think about:

Human Rights Issues

Human Rights Violations

Human Rights Questions

Human Rights Situations

The Dignity of Risk

It is vital to remember that the adults we support are fully adults. When considering the idea of risk, we may want to ask questions such as “What supports would we put in place for ourselves or friends or family who want to do things they've never done before? When planning new experiences, the DSP can use some of these tips:

- Talk about things before you experience them
- Research the best safety practices and decide if it makes sense for the current situation
- Try something for a short period of time and see if it is a success
- Try doing something with someone who has more experience than we do
- Evaluate the experience and make new decisions about going forward.

THE DIGNITY OF RISK

Have the DSPs read *The Dignity of Risk* and then discuss it in class.

Human Rights Scenarios

Allow 10-15 minutes for the group to discuss each scenario. Have them take turns reporting their thoughts for each.

Scenarios 1-3

After reading the scenarios, prompt with questions such as *"How could you help to be an advocate in each of these situations?"*

Presenter Script

"As a DSP, you work more closely on a daily basis with an individual you will be supporting than anyone else. Therefore, you are sometimes in the best position to understand the real issues. This is one of the reasons it is so important for you to be in regular communication with your supervisor and Interdisciplinary Team (IDT)."

Scenario 4

DISCUSS: What skills would we want to make sure are in place before Susan gets to do what she wants?

Some of the issues DSPs may bring up include:

- Ability to cross the street
- Socialization with strangers
- Ability to count change for purchases

DISCUSS: how to find the balance between allowing Susan to exercise her rights, but, at the same time, ensuring her safety.

After the DSPs have read *"The Dignity of Risk,"* explain and how important it is for the DSP to assist the individual in making their own decisions. We often want to make decisions for them, but discuss: **"Why is this not a good idea?"**

Bring up the following:

- Creates dependency
- Takes control of individuals life away from him/her
- Removes opportunities for choice

DISCUSS: It is the DSP's job to prepare the individual to follow through on whatever the person's choice is, but also minimize the risks associated with choice.

Scenario 5

DISCUSS:

Mental Health & Developmental Disabilities Confidentiality **Act**

<http://www.ilga.gov/legislation/>

An important role of the DSP is to protect the privacy of people they support.

Scenario 6

DISCUSS:

- Agency policies regarding negligence of duties
- Importance of respect and the DSP's role in facilitating the person's choices.
- Functional Activities and the role of a DSP as advocate providing supports that ensure that people they support are viewed with respect as well as valuable members of their community.
- The importance of modeling good behavior to persons supported as well as the community at large.

CONCLUSION OF TRAINING

Ask trainees what questions they have and carefully go over them.

Spend a few minutes introducing the On-the-Job (OJT) Training activities and Competency-Based Training Assessments (CBTAs) for this module.

Last page