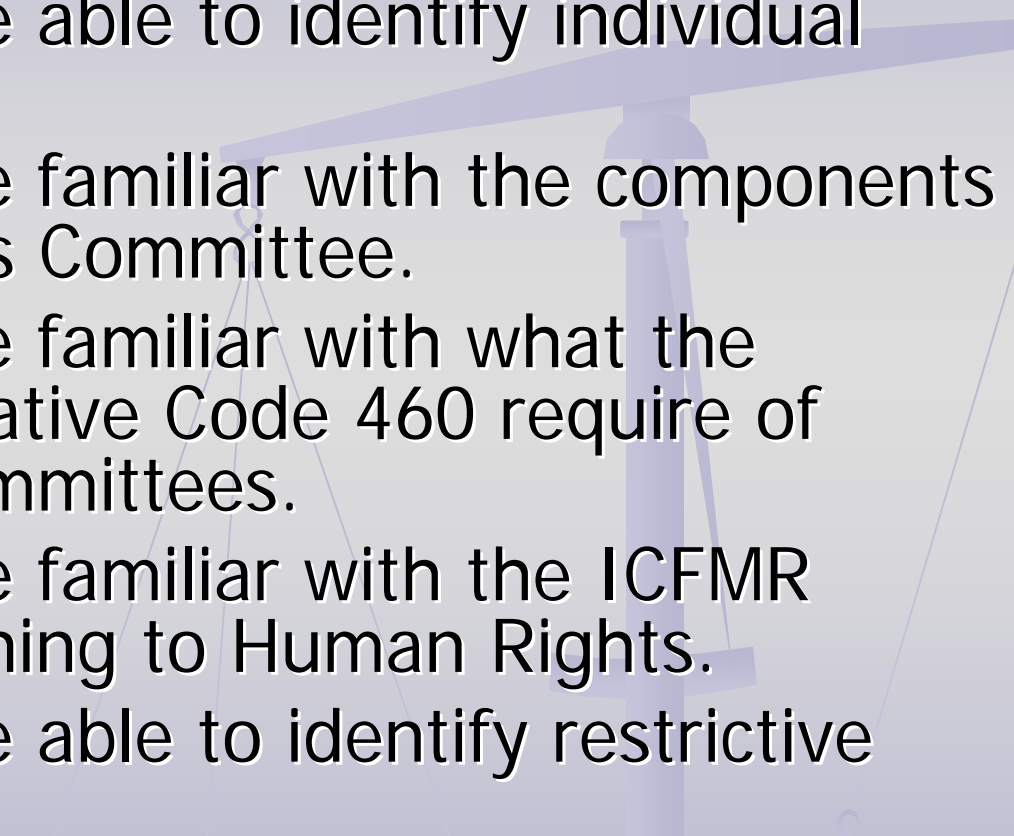




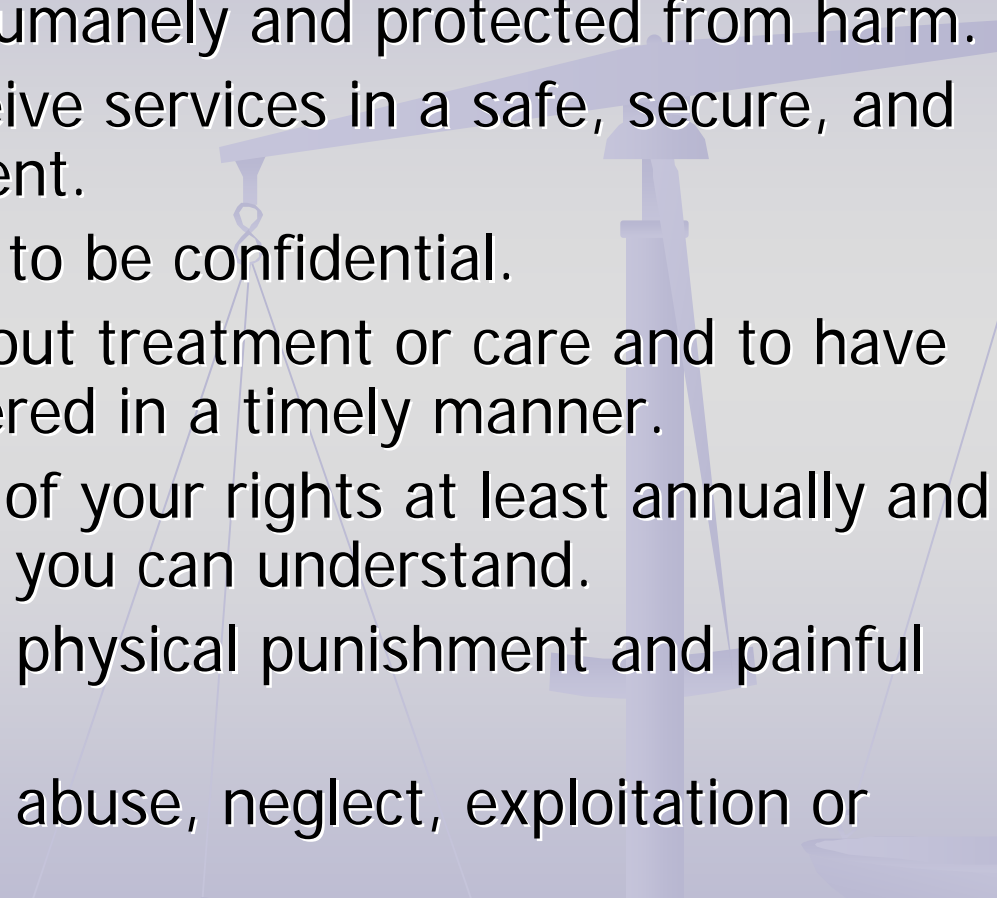
# Human Rights and Human Rights Committees

Presented by  
Southeast Indiana Outreach Services  
Judy Sides

# Learning Objectives

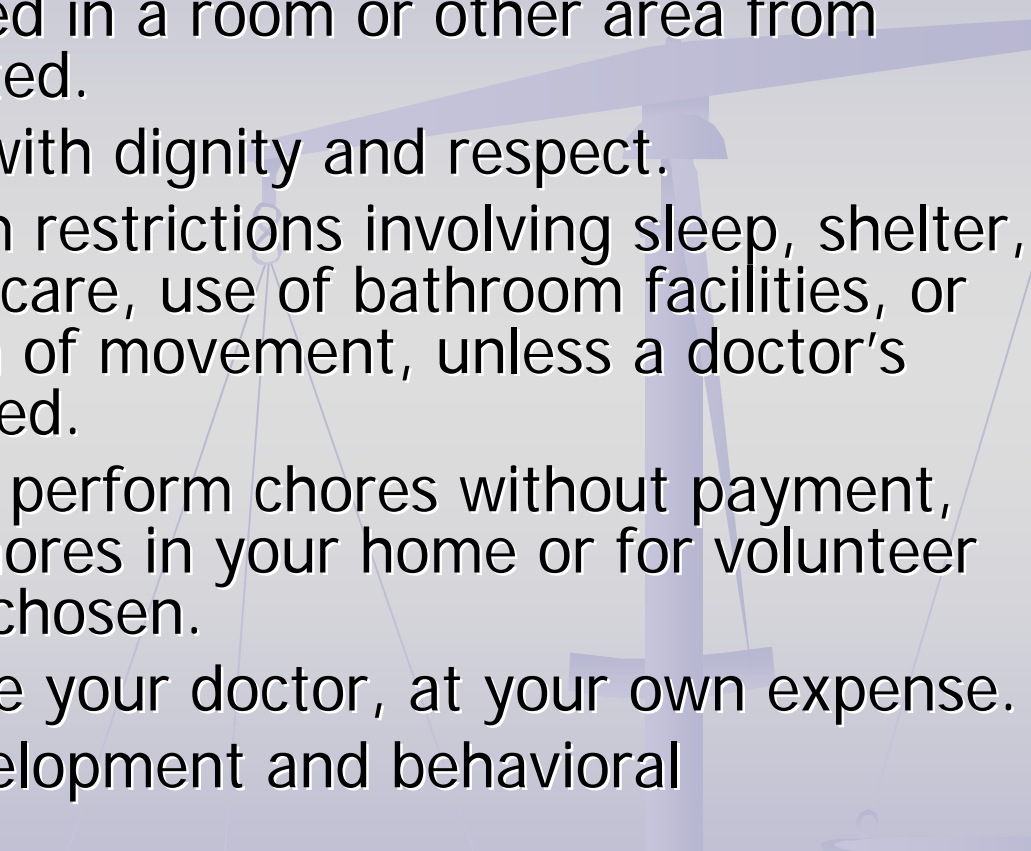
- The learner will be able to identify individual rights.
  - The learner will be familiar with the components of a Human Rights Committee.
  - The learner will be familiar with what the Indiana Administrative Code 460 require of Human Rights Committees.
  - The learner will be familiar with the ICFMR regulations pertaining to Human Rights.
  - The learner will be able to identify restrictive interventions.
- 

# Developmental Disability Rights (Source: Indiana's BDDS Guide)

- Right to be treated humanely and protected from harm.
  - Right to live and receive services in a safe, secure, and supportive environment.
  - Right for information to be confidential.
  - Right to complain about treatment or care and to have that complaint answered in a timely manner.
  - Right to be informed of your rights at least annually and in a manner in which you can understand.
  - Right to be free from physical punishment and painful treatment.
  - Right to be free from abuse, neglect, exploitation or mistreatment.
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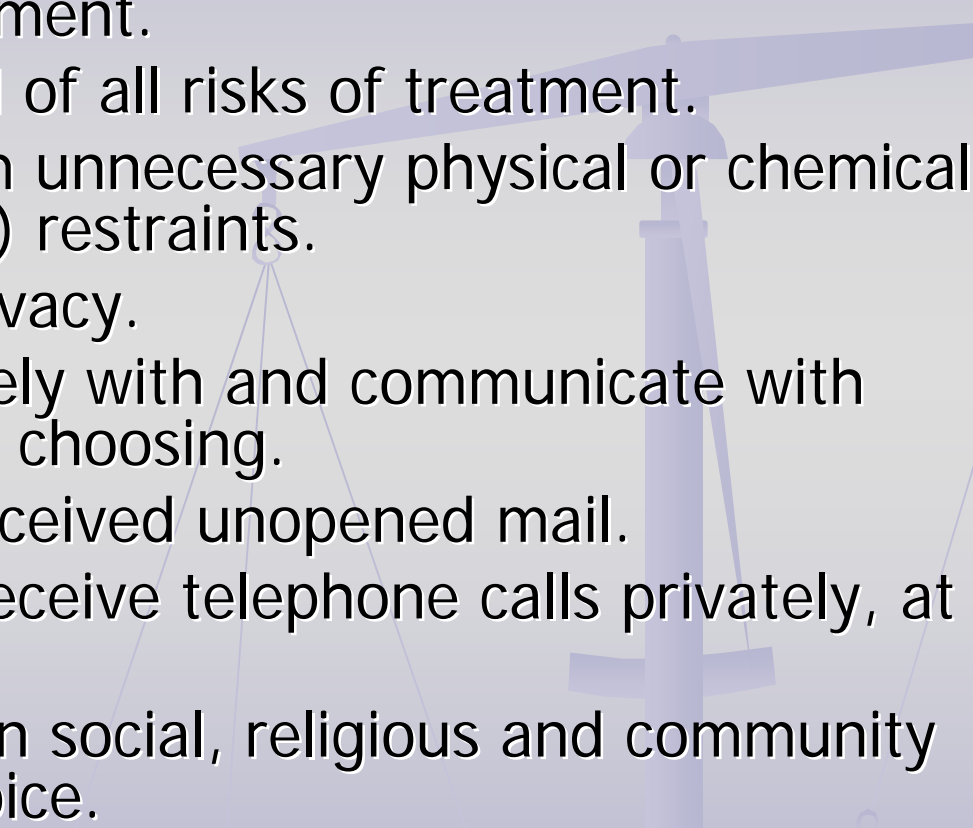
# Rights

## (Source: BDDS Guide)

- Right to not be placed in a room or other area from which exit is prevented.
  - Right to be treated with dignity and respect.
  - Right to be free from restrictions involving sleep, shelter, food, drink, medical care, use of bathroom facilities, or prolonged restriction of movement, unless a doctor's order is being followed.
  - Right to not work or perform chores without payment, except for normal chores in your home or for volunteer work that you have chosen.
  - Right to regularly see your doctor, at your own expense.
  - Right to regular development and behavioral assessments.
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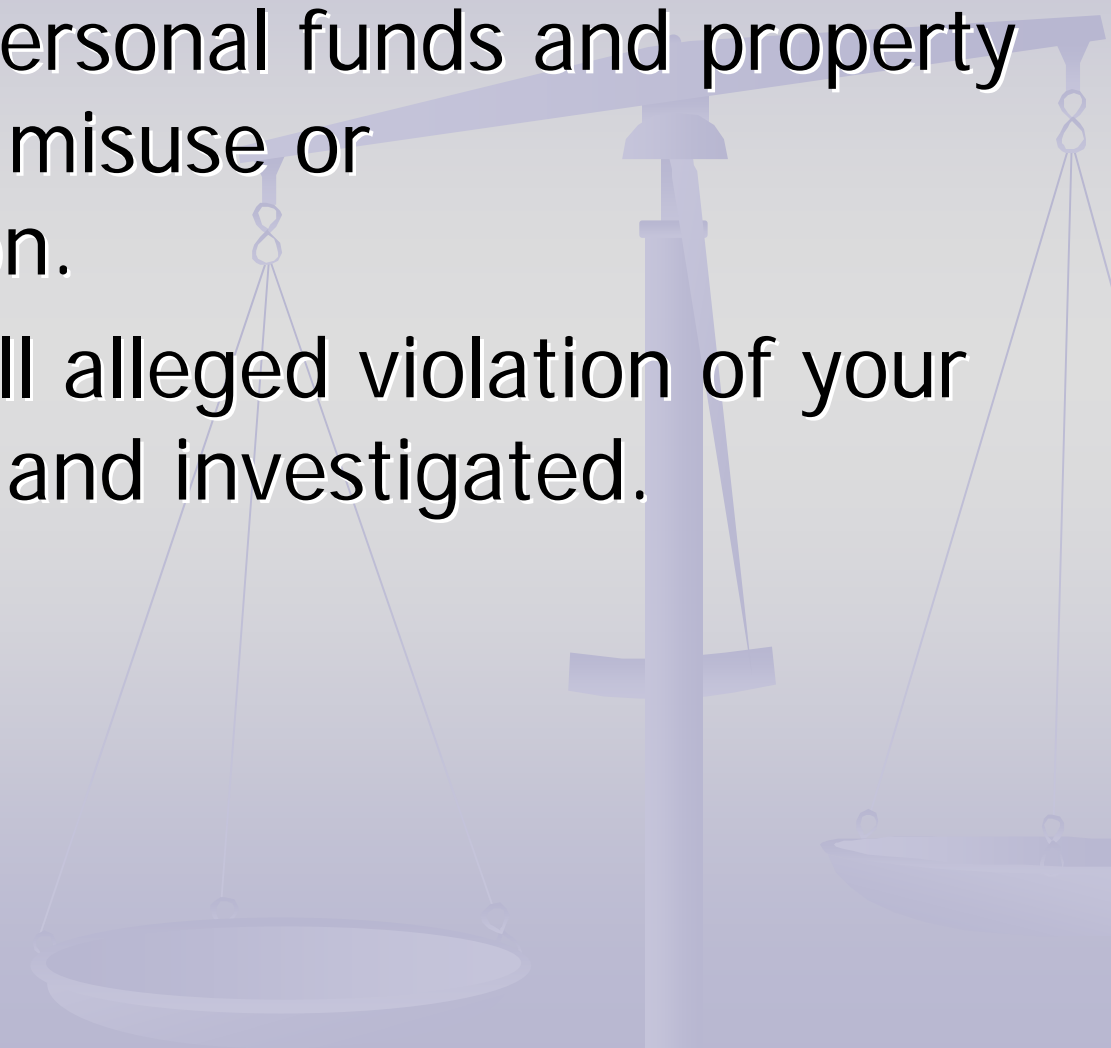
# Rights

## (Source: BDDS Guide)

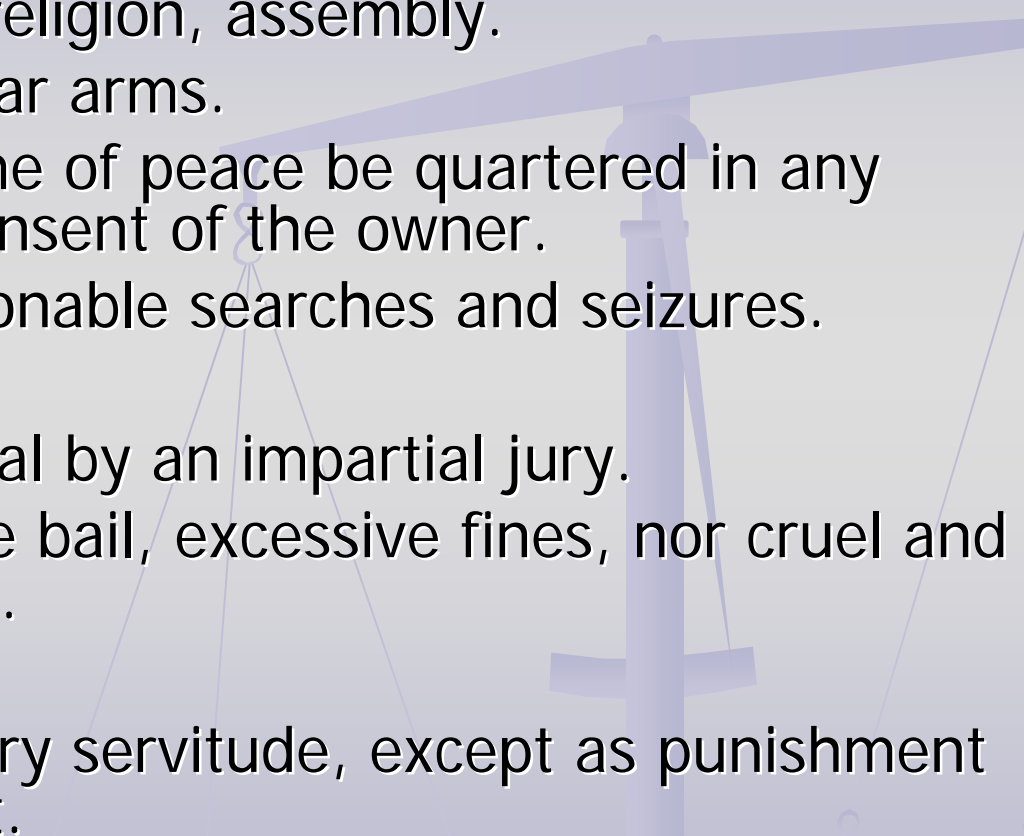
- Right to refuse treatment.
  - Right to be informed of all risks of treatment.
  - Right to be free from unnecessary physical or chemical (medication induced) restraints.
  - Right to personal privacy.
  - Right to meet privately with and communicate with persons of your own choosing.
  - Right to send and received unopened mail.
  - Right to make and receive telephone calls privately, at your own expense.
  - Right to participate in social, religious and community activities of your choice.
- 

# Rights

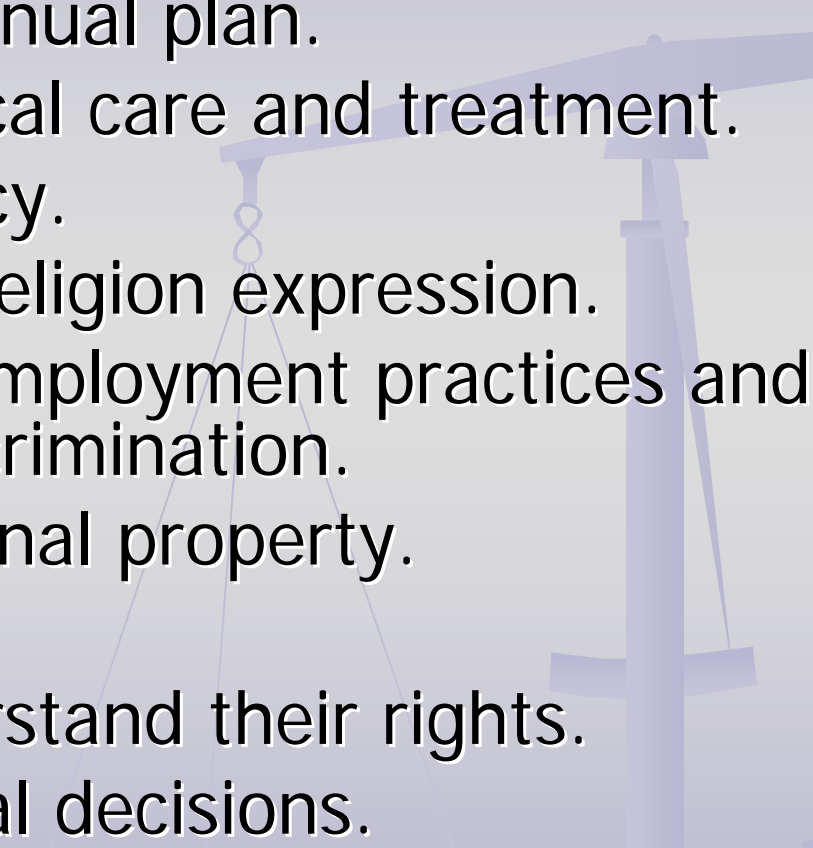
(Source: BDDS Guide)

- Right to have personal funds and property protected from misuse or misappropriation.
  - Right to have all alleged violation of your rights reported and investigated.
- 

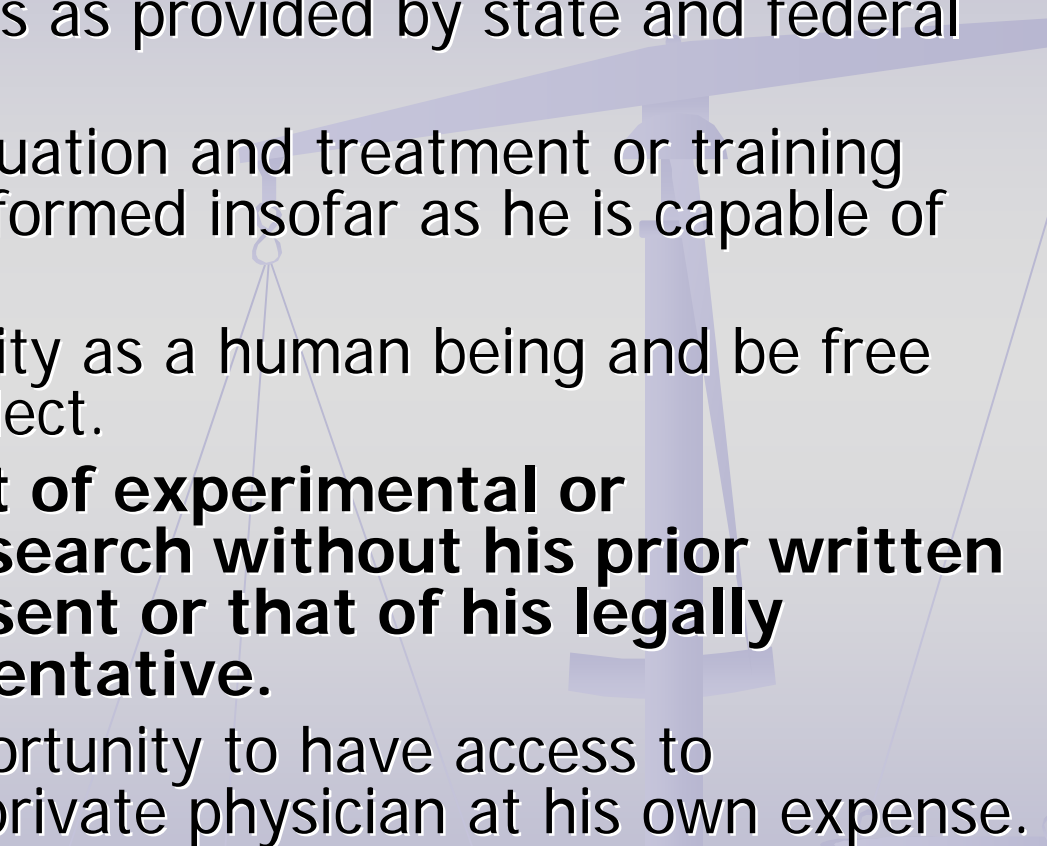
# Bill of Rights

- Freedom of speech, religion, assembly.
  - Right to keep and bear arms.
  - No soldier shall in time of peace be quartered in any house without the consent of the owner.
  - Right against unreasonable searches and seizures.
  - Due process of law.
  - Speedy and public trial by an impartial jury.
  - Not to have excessive bail, excessive fines, nor cruel and unusual punishments.
  - Vote.
  - Slavery nor involuntary servitude, except as punishment for a crime shall exist.
- 

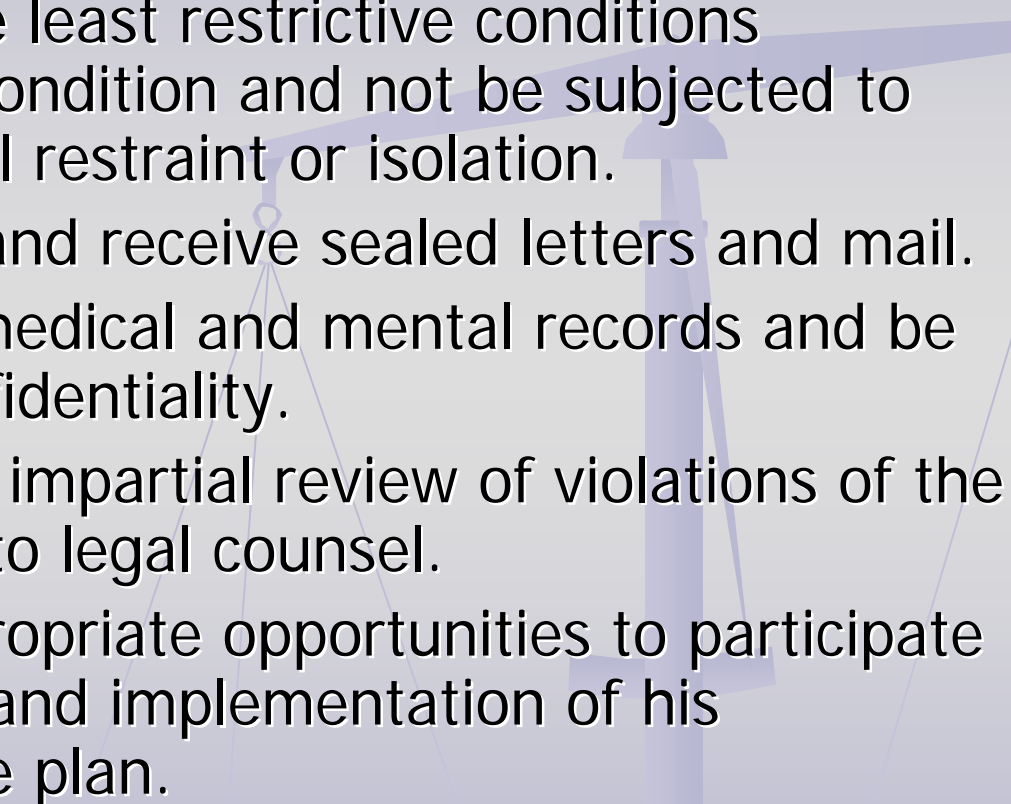
# Summary of Rights for People with Developmental Disabilities

- The right to an annual plan.
  - The right to medical care and treatment.
  - The right to privacy.
  - The right to free religion expression.
  - The right to fair employment practices and freedom from discrimination.
  - The right to personal property.
  - The right to vote.
  - The right to understand their rights.
  - The right to appeal decisions.
- 

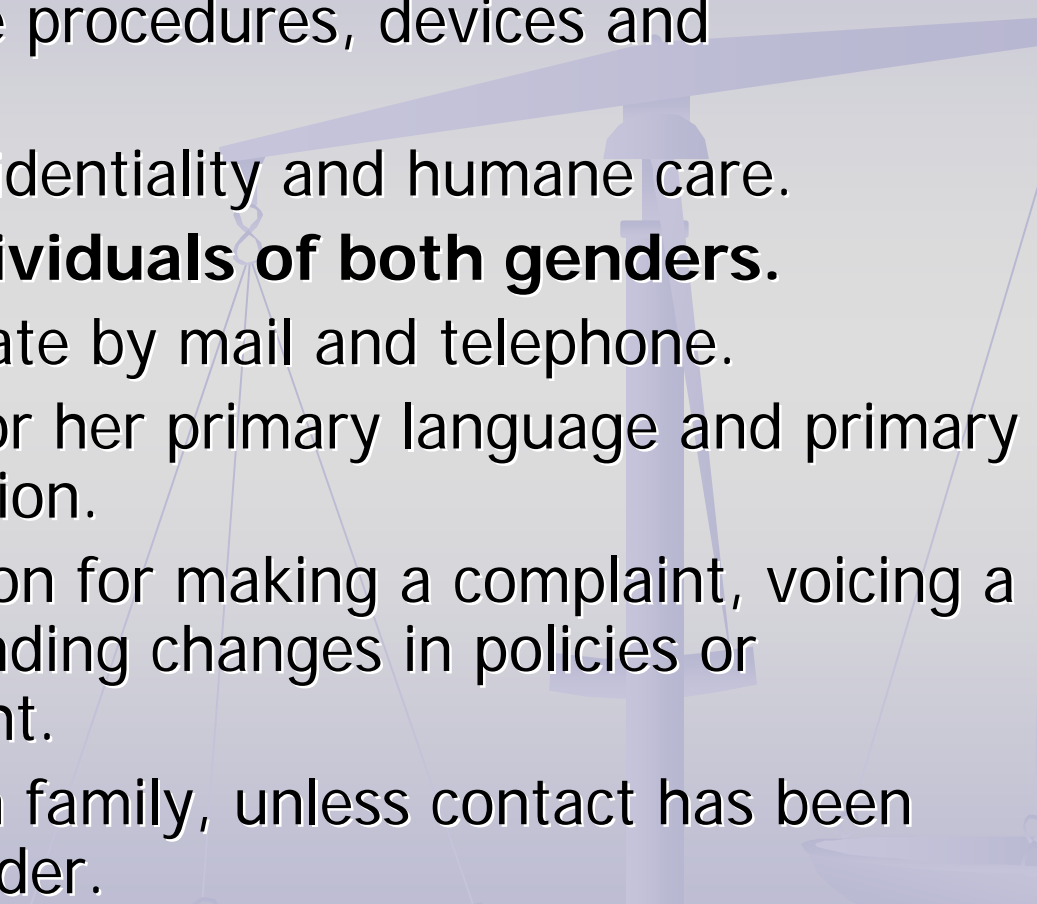
# Code of Virginia: Each consumer has the right to:

- Retain his legal rights as provided by state and federal law.
  - Receive prompt evaluation and treatment or training about which he is informed insofar as he is capable of understanding.
  - Be treated with dignity as a human being and be free from abuse and neglect.
  - **Not be the subject of experimental or investigational research without his prior written and informed consent or that of his legally authorized representative.**
  - Be afforded the opportunity to have access to consultation with a private physician at his own expense.
- 

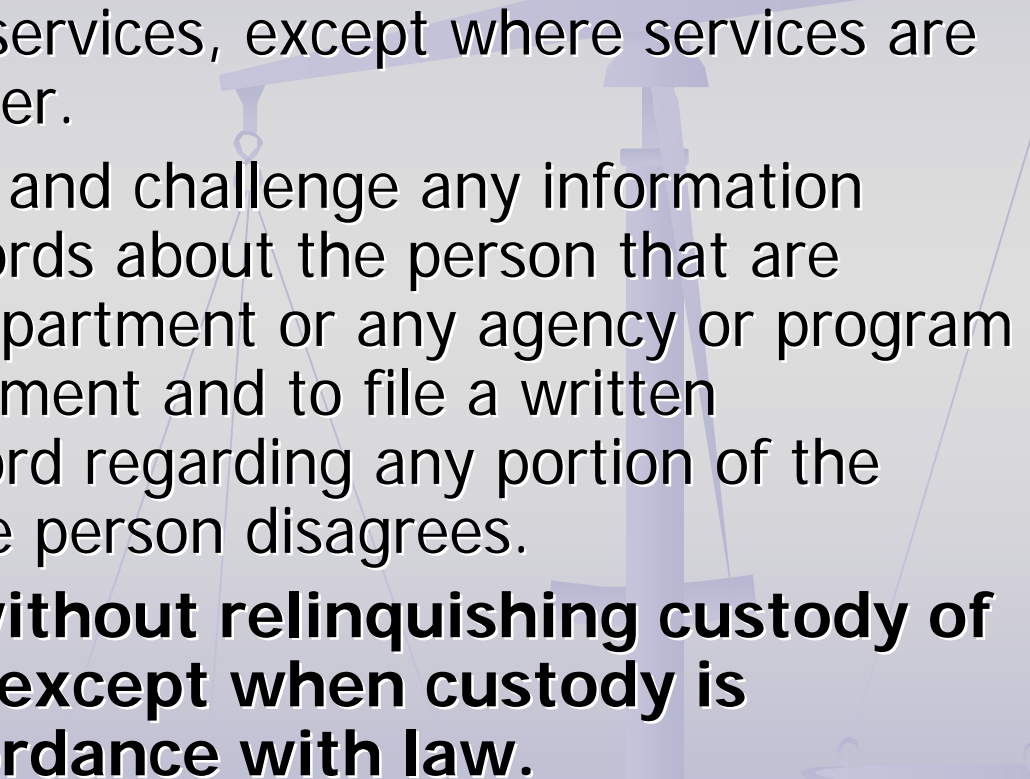
# Code of Virginia: Each consumer has the right to:

- Be treated under the least restrictive conditions consistent with his condition and not be subjected to unnecessary physical restraint or isolation.
  - Be allowed to send and receive sealed letters and mail.
  - Have access to his medical and mental records and be assured of their confidentiality.
  - Have the right to an impartial review of violations of the rights and the right to legal counsel.
  - Be afforded the appropriate opportunities to participate in the development and implementation of his individualized service plan.
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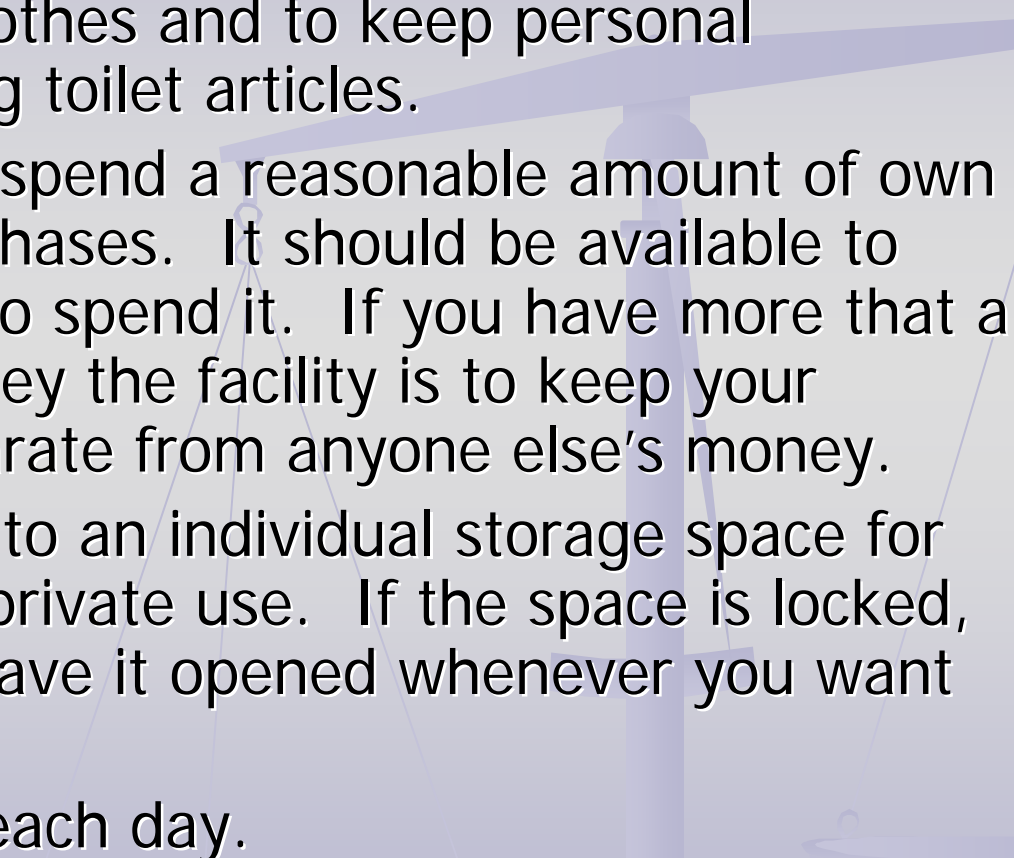
# Vermont: Rights of recipients according to the Developmental Disabilities Act

- Be free from aversive procedures, devices and treatments.
  - Privacy, dignity, confidentiality and humane care.
  - **Associate with individuals of both genders.**
  - Communicate in private by mail and telephone.
  - Communicate in his or her primary language and primary mode of communication.
  - Be free from retaliation for making a complaint, voicing a grievance, recommending changes in policies or exercising a legal right.
  - Maintain contact with family, unless contact has been restricted by court order.
- 

# Vermont: Rights of recipients according to the Developmental Disabilities Act

- Refuse or terminate services, except where services are required by court order.
  - Have access to, read and challenge any information contained in any records about the person that are maintained by the department or any agency or program funded by the department and to file a written statement in the record regarding any portion of the record with which the person disagrees.
  - **Receive services without relinquishing custody of a child or children except when custody is terminated in accordance with law.**
- 

# Rights in a California Developmental Center

- Right to wear own clothes and to keep personal possessions, including toilet articles.
  - Right to keep and to spend a reasonable amount of own money for small purchases. It should be available to you when you want to spend it. If you have more than a small amount of money the facility is to keep your money safe and separate from anyone else's money.
  - Right to have access to an individual storage space for your things for your private use. If the space is locked, you have a right to have it opened whenever you want to use it.
  - Right to see visitors each day.
- 

# Rights in a California Developmental Center

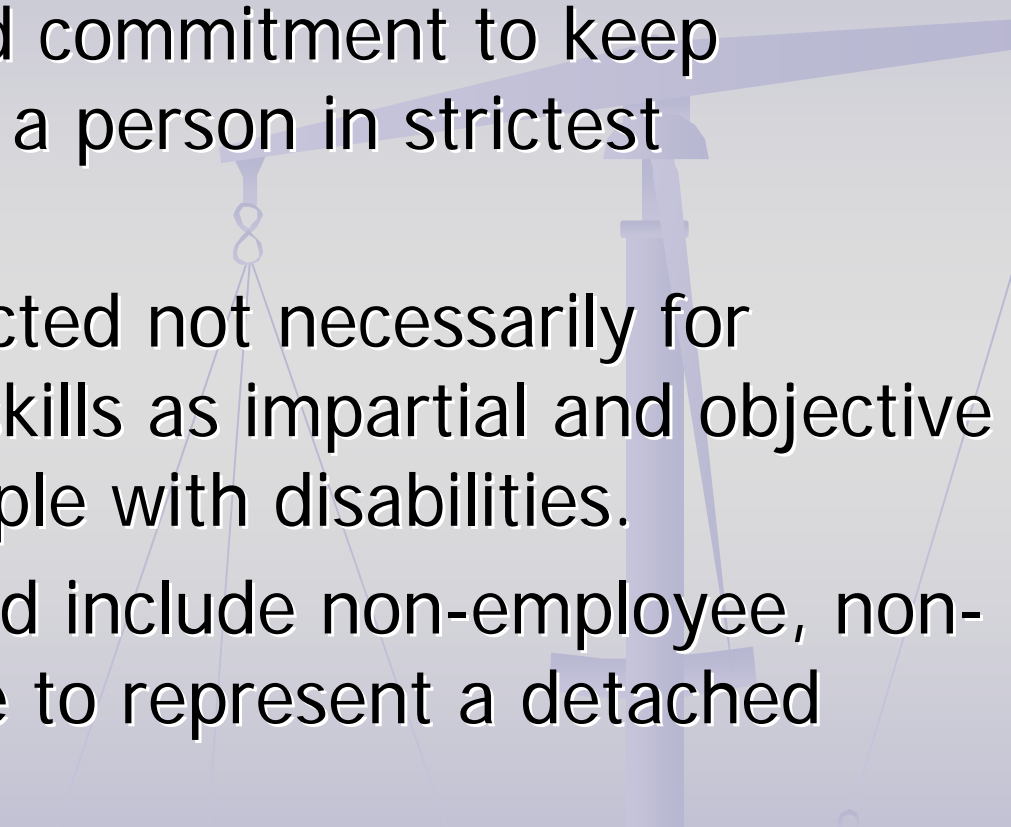
- Right to reasonable access to the telephone and to make and receive private and confidential calls. No one can listen in on your calls.
- Right to have ready access to letter writing materials, including postage stamps, and to send and receive letters unopened.
- **Right to refuse electroconvulsive therapy.**
- Right to refuse behavior modification techniques which cause pain or trauma.
- **Right to refuse psychosurgery, and all other surgery which is done for the purpose of brain or thought modification.**
- Right to make choices.

# Human Rights Committee




- Provides a third party review process required by law to safeguard the rights of people receiving services.
- Focuses on rights, not general conflicts that occur in the day to day delivery of service.
- Provides a review of proposed restraint procedures, review of policies, procedures, trends and patterns, individual situations and individual behavioral support plans that authorize the use of restraint procedures.

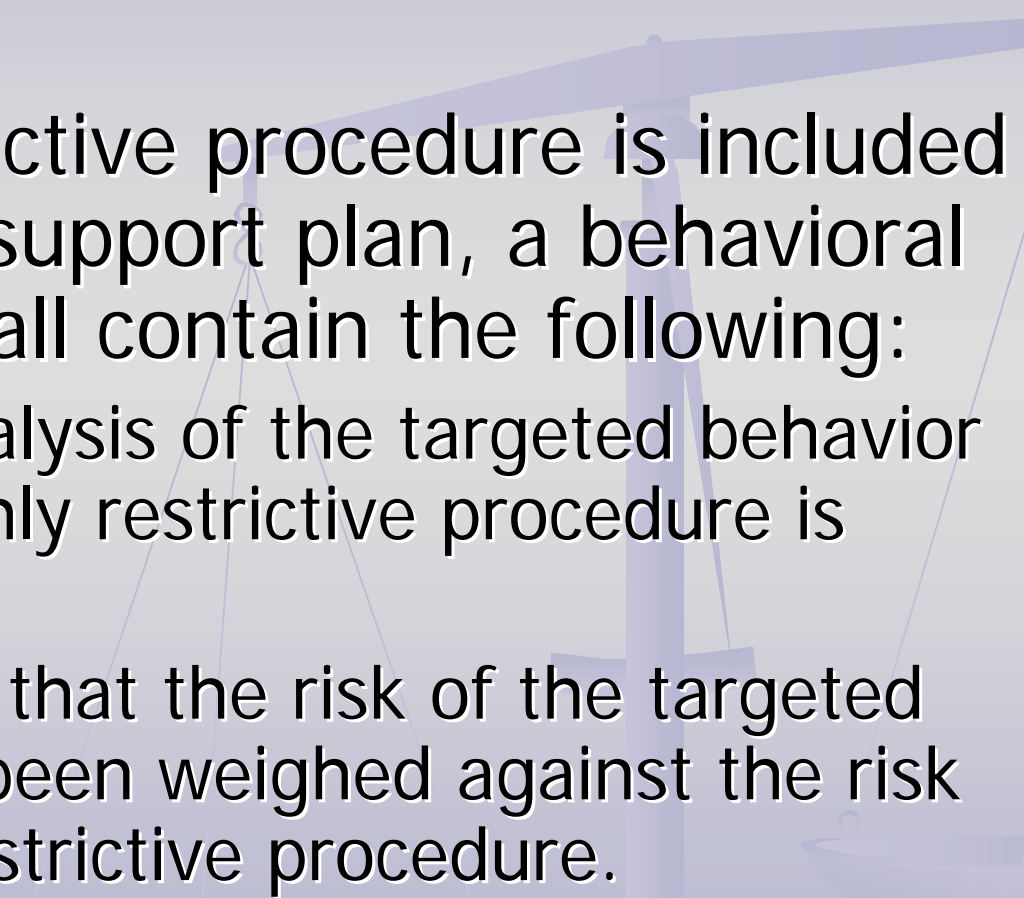
# Human Rights Committee

- Confidentiality and commitment to keep information about a person in strictest confidence.
  - Members are selected not necessarily for expertise but for skills as impartial and objective advocates for people with disabilities.
  - Membership should include non-employee, non-contractual people to represent a detached perspective.
- 

# Starting a HRC

- Define Functions of the Human Rights Committee
  - Composition of the Human Rights Committee
  - Submissions to the Human Rights Committee
  - Information to be submitted
  - Attendance at the review
  - Meeting process
  - After the meeting
- 

# IAC 460 for supported living

- 460 IAC 6-18-2
  - If a highly restrictive procedure is included in a behavioral support plan, a behavioral support plan shall contain the following:
    - A functional analysis of the targeted behavior for which a highly restrictive procedure is designed.
    - Documentation that the risk of the targeted behavior have been weighed against the risk of the highly restrictive procedure.
- 

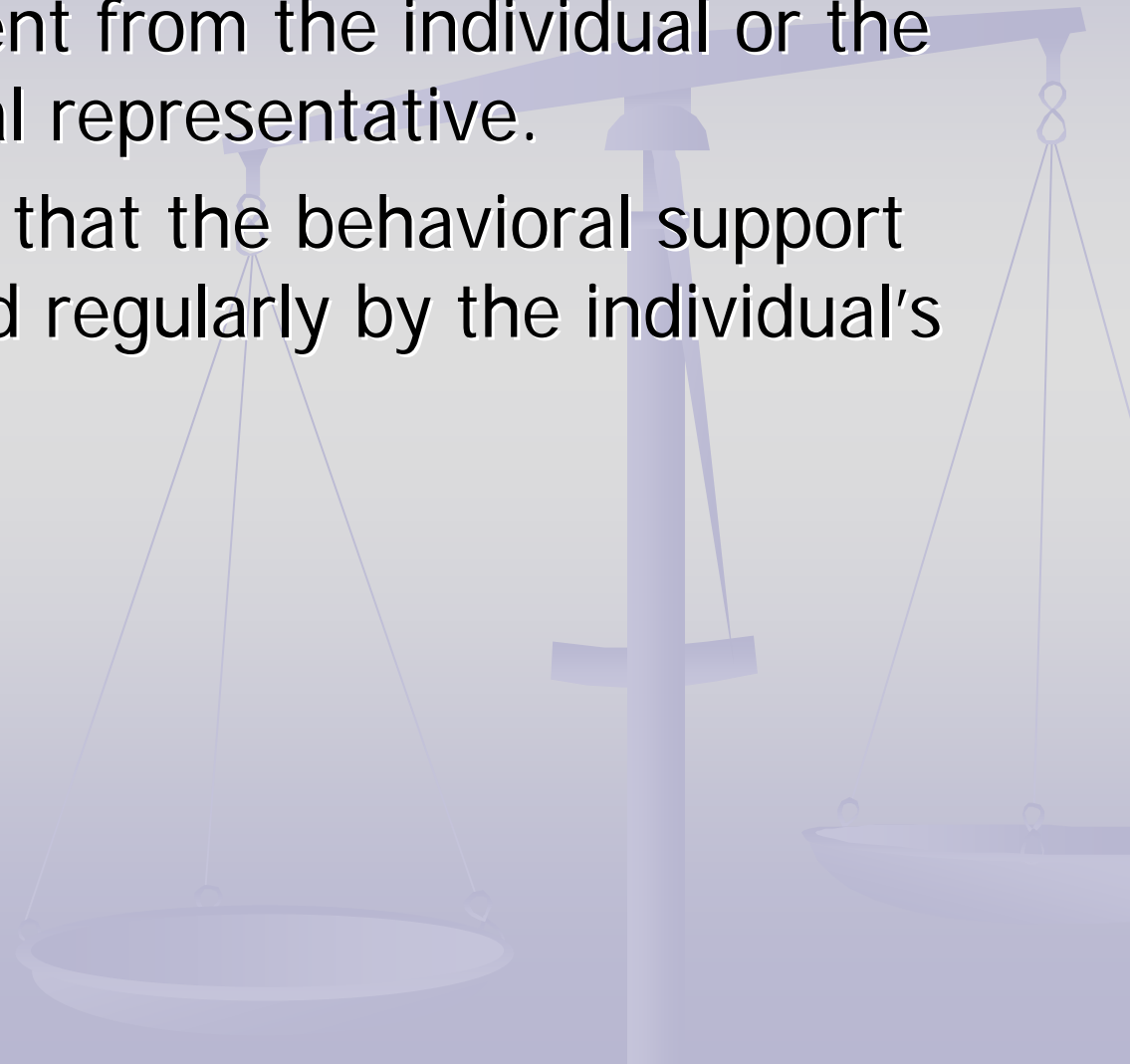
# IAC 460 for supported living



- Documentation that systematic efforts to replace the targeted behavior with an adaptive skill were used and found to be not effective.
- Documentation that the individual, the individual's support team and the applicable human rights committee agree that the use of the highly restrictive method is required to prevent significant harm to the individual or others.

# IAC 460 for supported living

- Informed consent from the individual or the individual's legal representative.
- Documentation that the behavioral support plan is reviewed regularly by the individual's support team.



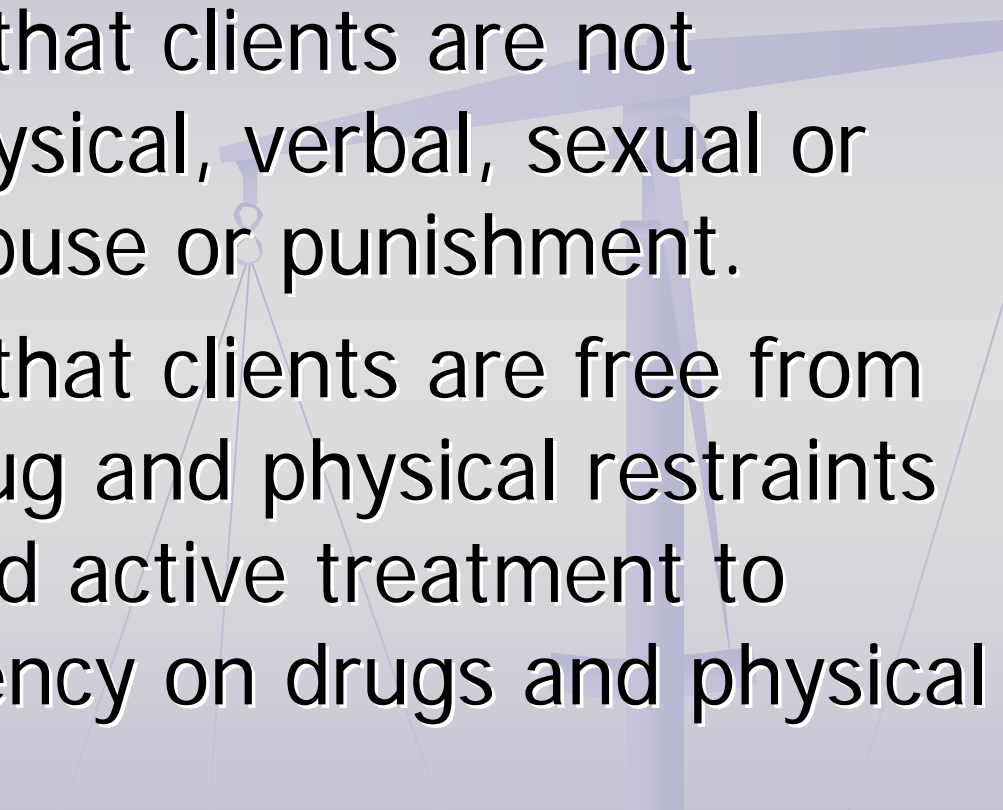
# ICFMR Regulations

- W122: Condition – Client Protections
  - Free from abuse, neglect, unnecessary drugs and restraints, and individual freedoms are promoted
- W123: Inform each client, parent (if the client is a minor), or legal guardian, of the client's rights and rules of the facility
- W124: Inform each client, parent, or legal guardian, of the client's medical condition, developmental and behavioral status, attendant risk of treatment, and of the right to refuse treatment.

# ICFMR Regulations

- W125: Allow and encourage individual client to exercise their rights as clients of the facility, and as citizens of the United States, including the right to file complaints, and the right to due process.
- W126: Allow individual clients to manage their financial affairs and teach them to do so to the extent of their capabilities.

# ICFMR Regulations

- W127: Ensure that clients are not subjected to physical, verbal, sexual or psychological abuse or punishment.
  - W128: Ensure that clients are free from unnecessary drug and physical restraints and are provided active treatment to reduce dependency on drugs and physical restraints.
- 

# ICFMR Regulations



- W129: Provide each client with the opportunity for personal privacy.
- W130: Ensure privacy during treatment and care of personal needs.
- W131: Ensure that clients are not compelled to perform services for the facility.

# ICFMR Regulations

- W132: Ensure that clients who do work for the facility are compensated for their efforts at prevailing wages and commensurate with their abilities
- W133: Ensure clients the opportunity to communicate, associate, and meet privately with individuals of their choice.
- W134: Send and receive unopened mail

# ICFMR Regulations

- W135: Ensure that clients have access to telephones with privacy for incoming and outgoing local and long distance calls except as contraindicated by factors identified within their individual program plans.
- W136: Ensure clients the opportunity to participate in social, religious, and community group activities.

# ICFMR Regulations

- W137: Ensure that clients have the right to retain and use appropriate personal possessions and clothing.
- W138: Ensure that each client is dressed in his or her own clothing each day.
- W139: Permit a husband and wife who both reside in the facility to share a room.

# ICFMR Standards for Human Rights Committee

- W261: The facility must designate and use a specially constituted committee or committees consisting of members of facility staff, parents, legal guardians, clients (as appropriate), qualified persons who have either experience or training in contemporary practices to change inappropriate client behavior, and person with no ownership or controlling interest in the facility.
- W262: (To) review, approve, and monitor individual programs designed to manage inappropriate behaviors and other programs that, in the opinion of the committee, involve risks to client protection and rights;
- W263: Insure that these programs are conducted only with the written informed consent of the client, parents (if client is a minor), or legal guardian, and;
- W264: Review, monitor and make suggestions to the facility about its practices and programs as they relate to drug usage, physical restraints, time-out rooms, application of painful or noxious stimuli, control of inappropriate behavior, protection of client rights and funds, and any other area that the committee believes need to be addressed

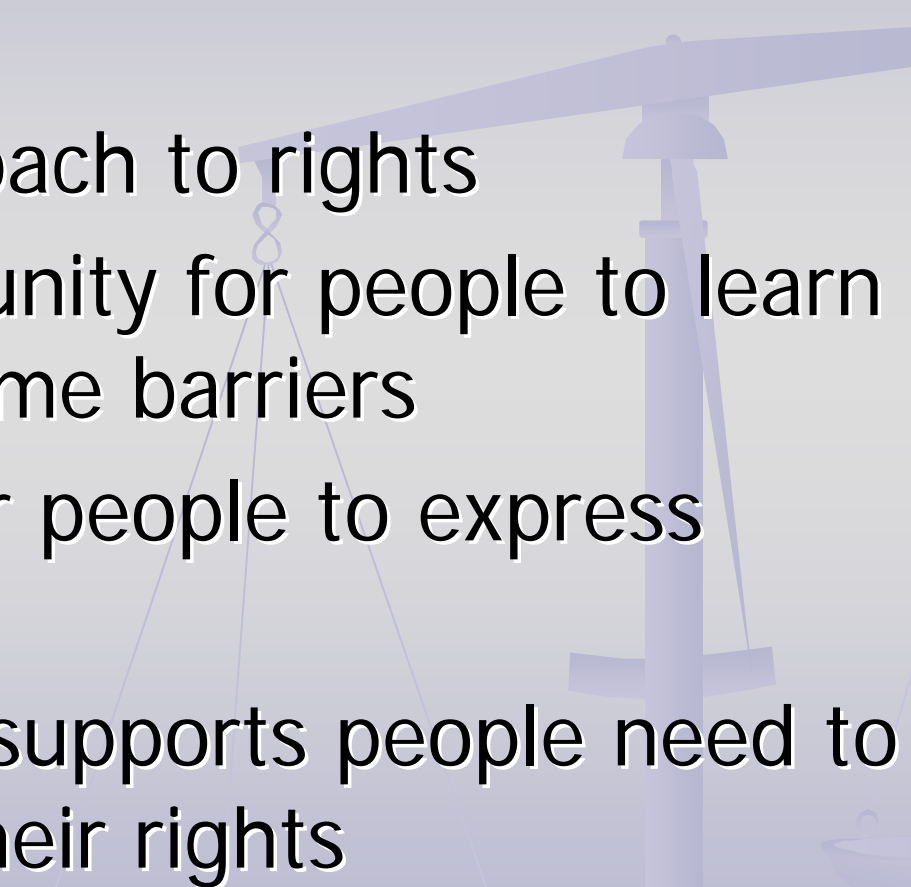
# Restrictive/Aversive Interventions

## ICFMR Definitions

- Time-out rooms
- Physical Restraint
- Drugs to manage inappropriate behavior
- Painful or noxious stimuli
- Any denial of rights

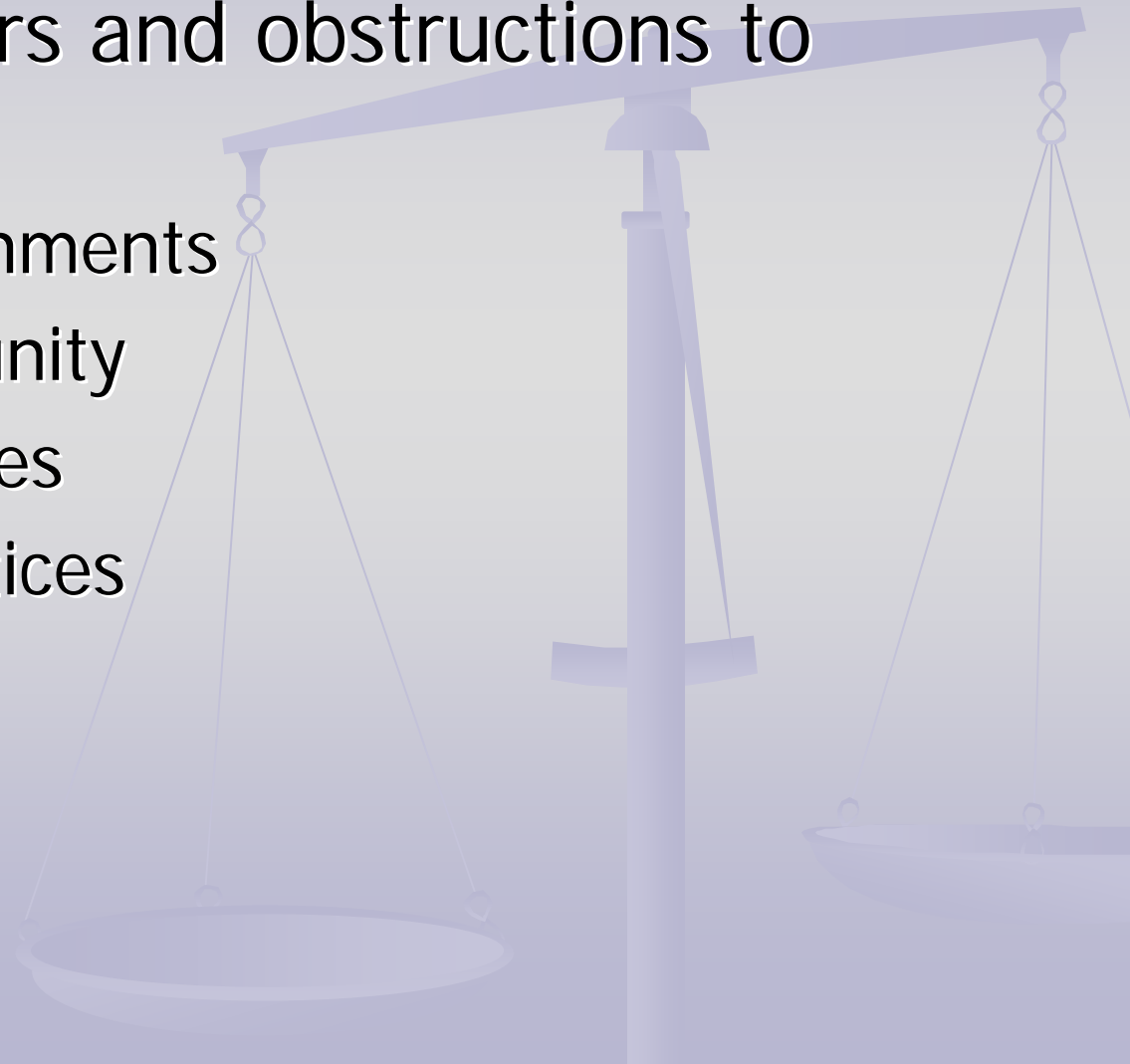


# Facilitating People to Exercise Their Rights

- Facilitators
  - Proactive approach to rights
  - Provide opportunity for people to learn ways to overcome barriers
  - Create ways for people to express opinions
  - Consider what supports people need to fully exercise their rights
- 

# Enabling People to Exercise Their Rights

- Eliminate barriers and obstructions to liberties
  - Physical environments
  - Lack of opportunity
  - Lack of resources
  - Rules and Practices

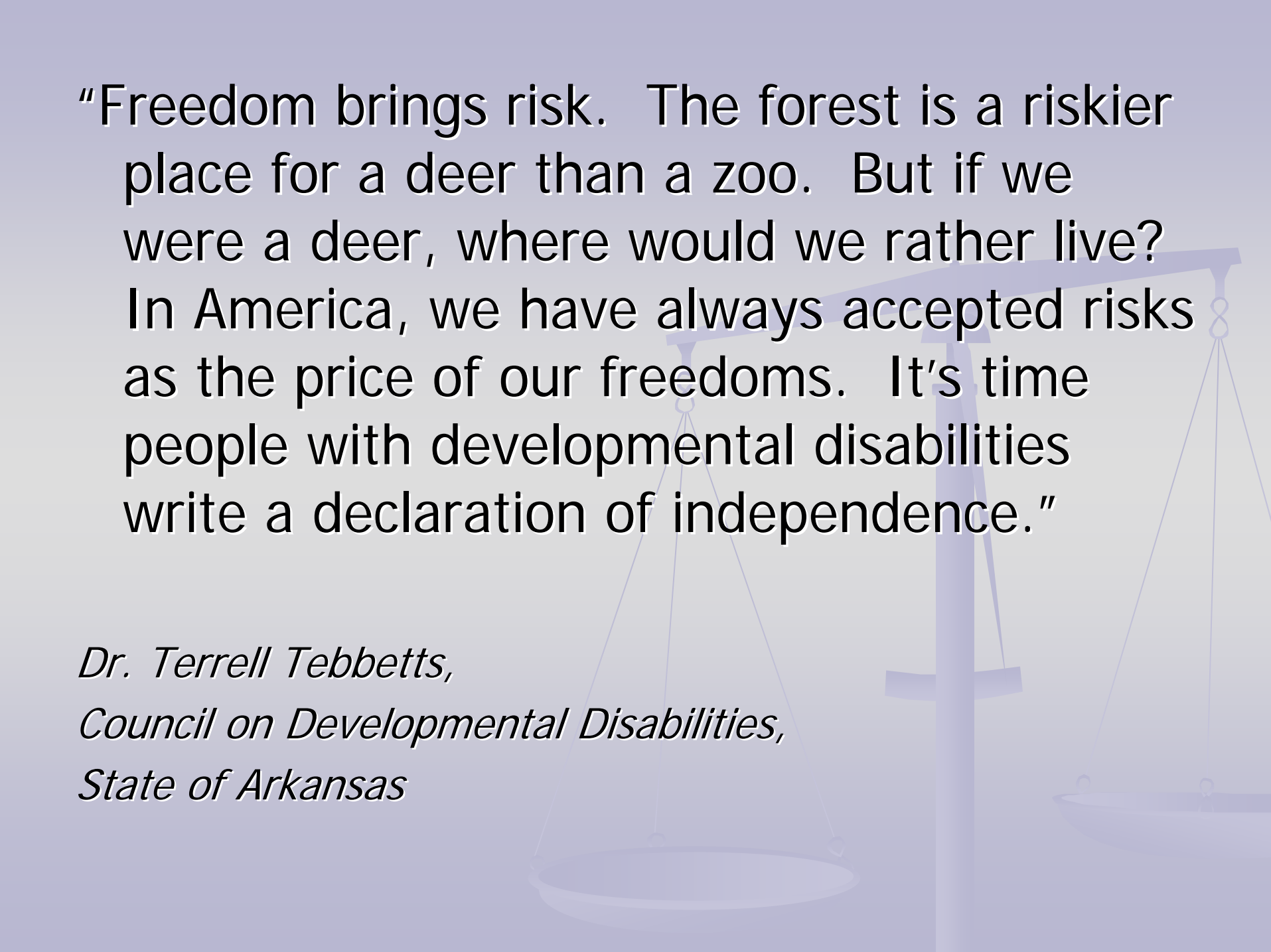


# Rights and Risks



- Risk is the possibility of suffering harm or loss; danger. A factor, thing, element, or course involving uncertain danger; a hazard. To expose to a chance of loss or damage; hazard.

*The American Heritage College Dictionary*

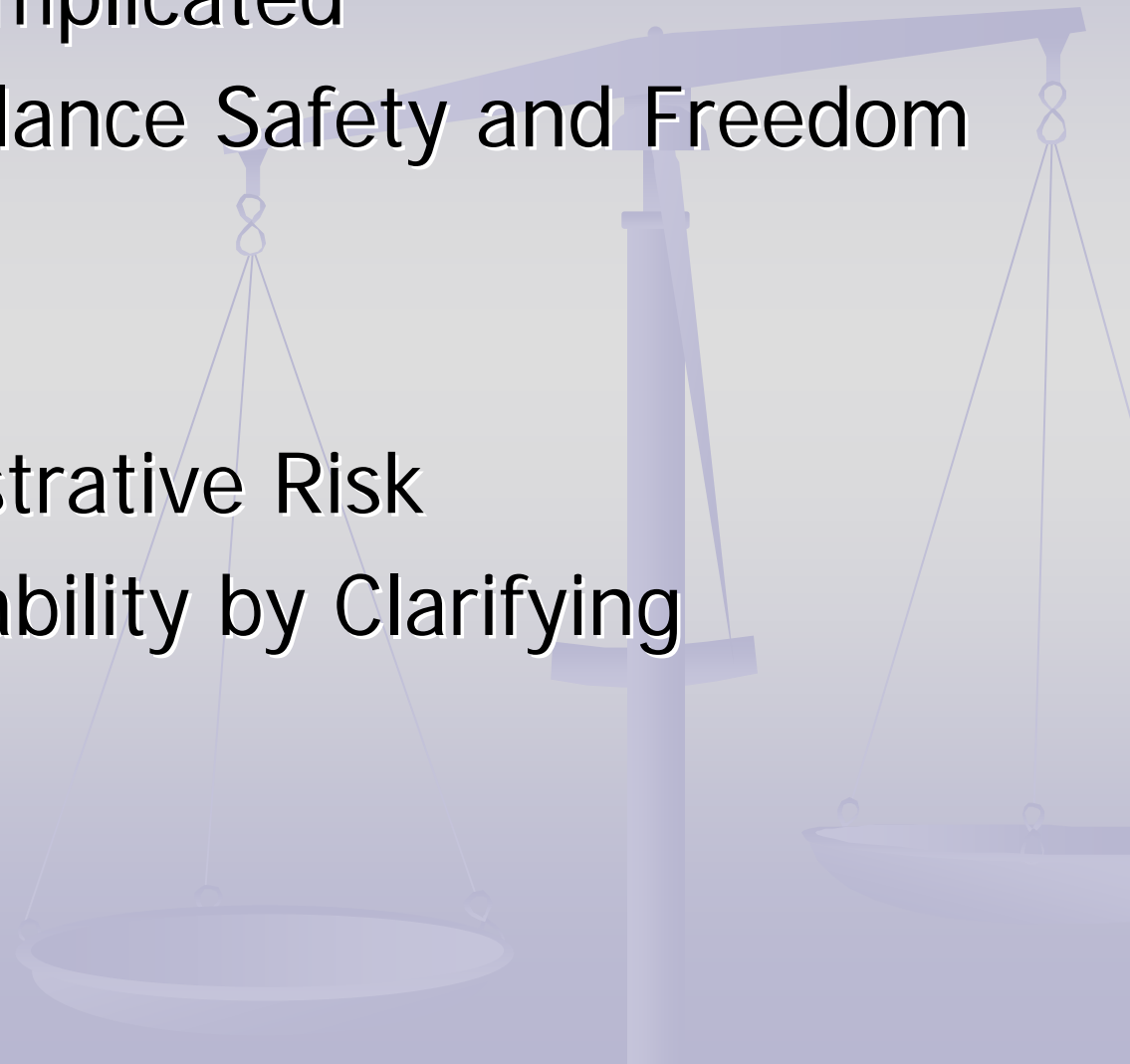


“Freedom brings risk. The forest is a riskier place for a deer than a zoo. But if we were a deer, where would we rather live? In America, we have always accepted risks as the price of our freedoms. It’s time people with developmental disabilities write a declaration of independence.”

*Dr. Terrell Tebbetts,  
Council on Developmental Disabilities,  
State of Arkansas*

# Rights and Risks

- The Challenge
- The Issue is Complicated
- The Need to Balance Safety and Freedom
- Individual Risk
- Program Risk
- System/Administrative Risk
- Reduction of Liability by Clarifying Function



# Resources

- *The American Heritage College Dictionary*
- *Enhancing Rights: A Proactive Approach. The Council on Quality and Leadership in Supports for People with Disabilities*
- *All About Rights: A guide to Supporting the Rights of People with Intellectual Disabilities. The Council on Quality and Leadership in Supports for People with Disabilities.*
- *Human Rights Committees: Keeping Organizations on Course. Steve Baker and Amy Tabor*
- *Interpretive Guidelines- Intermediate Care Facilities for Persons with Mental Retardation*
- *Indiana Administrative Codes 460 for Supported Living*
- *Balancing Safety and Freedom, Charles Moseley, Ed.D.*
- *Your Rights as an Adult Receiving Treatment in a Mental Health Facility in Indiana. March 2002. Indiana Protection and Advocacy Services.*
- *Position Statements. The Arc, Congress of delegates, November 9, 2002. AAMR*
- *A guide for Individuals working with the Bureau of Development Disabilities Services.*  
<http://www.in.gov/fssa/servicedisabl/bqis/bddsguide.htm>
- *A Guide to Disability Rights Laws. September 2005. U.S. Department of Justice. [www.ada.gov/cguide.htm](http://www.ada.gov/cguide.htm)*
- *AAMR Fact Sheet: Human Rights. [www.aamr.org](http://www.aamr.org)*
- *In the Name of Treatment. The Alliance to Prevent Restraint, Aversive Interventions, and Seclusion. 2005 [www.aprais.org](http://www.aprais.org)*
- *Human Rights Committee. Denver Options. [www.denveroptions.org/hrc.htm](http://www.denveroptions.org/hrc.htm)*
- *A Summary of Rights for People with Developmental Disabilities. Denver Options. [www.denveroptions.org/rightslist.htm](http://www.denveroptions.org/rightslist.htm)*
- *Rights Under the Lanterman Act. [www.pai-ca.org/pubs/506301.htm](http://www.pai-ca.org/pubs/506301.htm)*
- *Ethical and Legal Issues: Participant Manual. State of Oklahoma Department of Human Service Developmental Disabilities Service Division*
- *Universal Declaration of Human Rights. [www.state.gov/g/drl/hr/60372.htm](http://www.state.gov/g/drl/hr/60372.htm)*
- *Poyner & Spruill. Attorneys at Law. [www.poynerspruill.com/infocenter](http://www.poynerspruill.com/infocenter)*
- *State of Vermont Developmental Disability Services. [www.dad.state.vt.us/DSwebsite/boards/da/ds-human-rights.html](http://www.dad.state.vt.us/DSwebsite/boards/da/ds-human-rights.html)*
- *AAMR. Wyatt v. Stickney – A long Odyssey Reaches an End. [www.aamr.org/Reading\\_Room/pdf/wyatt.shtml](http://www.aamr.org/Reading_Room/pdf/wyatt.shtml)*

# Activity

- Review a Human Rights Committee submission.



# Contact Information

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<http://www.in.gov/fssa/disability/services/seoutreach/index.html>