

# HUMAN RIGHTS



What families need to know

## OUR AGENDA

- The basic Human Rights for people served by the Department of Developmental Services (DDS)
- Limitations on the rights
- How families can make a positive impact
- Solving human rights issues



# GENERAL PRINCIPLES



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- Services provide humane and adequate care
- Services teach independence
- Services promote social inclusion
- Services encourage self determination



## QUALITY OF CARE

### You should expect Services for your family member to be provided with care and respect

- They should be well taken care of; free from discomfort, distress, and deprivation.
- Staff should know about any special support needs and preferences of the person.
- Staff need to communicate to your family member calmly, respectfully, and in an age appropriate manner.
- **They need to be attentive to your family member.**
- Choices are based on the individuals interests, not staff preferences.

## PERSONAL CARE WITH DIGNITY

- Staff need to provide good and thorough personal care so that your family member is clean, comfortable and properly dressed.
- Appearances do matter.
- People can have a reasonable expectation to get help with personal care from same sex staff that involves disrobing.



## HELPING PEOPLE TO BECOME MORE INDEPENDENT

- Services should teach **functional** and **meaningful** skills to people that they can use in their lives to become more independent.
- These should be geared to each person's needs, abilities, and interests.



## INDEPENDENCE

- Services and supports need to be provided in the **least restrictive** way possible.
- Staff should provide only as much assistance as is needed, they should encourage the individual to do as much as they can, so as to avoid learned helplessness.
- Restrictions must be as minimal as possible to insure safety.



## SERVICE PROMOTE BELONGING

- People should be supported to dress and conduct themselves in the community in an age appropriate way that will promote community membership.



## TAKING CHARGE

- People are in charge of their own lives.
- They get to make important decisions about their lives.
- This includes opportunities to make choices about what to eat and drink, how to spend their leisure time, when to go to bed, how to spend their money.



## DECISIONS AND RISKS

- People have a right to make decisions. Some of those decisions may not be what others think are best.
- It is important to educate and encourage people about the variety of choices that are available, otherwise they may just stick to what they already know. Families can be an important source of information.
- Sometimes the best way to learn is by making mistakes. It is part of life, **unless the individual's safety and well-being are unreasonably jeopardized.**

## COMMUNICATION

- People can communicate with others in whatever way they choose.
- People should receive the help that they need to communicate in the way that works best for them.



## TO VISIT AND BE VISITED AT HOME

- People can have visitors and visit others. It is their home, after all.
- Staff should be polite and courteous to visitors.
- Visitors also should be considerate, since there may be other people living there too.



## PRIVACY

- People have a **reasonable** expectation of privacy.
- This can include spending time alone, communicating with family/friends, or having "private time" with visitors.



# POSSESSIONS

- People get to buy and keep their own things.
- They should have a place to safely keep their stuff.
- Possessions are not restricted unless they pose an immediate threat of serious physical harm to the individual or other persons.



## Disability Law Center

### **Our Mission**

To provide legal advocacy on disability issues that promote the fundamental rights of all people with disabilities to participate fully and equally in the social and economic life of Massachusetts.





## DLC

- Serves people with all types of disabilities with disability-related legal issues
- Legal problems must fall within a DLC priority area
  - Annual priorities are adopted with input from the disability community
  - A full list is available on the webpage: <http://www.dlc-ma.org>

## Protection and Advocacy

- DLC is the protection and advocacy agency for Massachusetts.
- Protection and Advocacy agencies (PNAs) are disability rights agencies investigating abuse and neglect and providing legal representation in other advocacy services.
- Every state must have a designated protection and advocacy agency.

## Office for Human Rights

- Ensures that services:
  - Are sufficient to meet the needs of the people
  - Are provided with respect and dignity
  - Teach people independence
  - Promote self determination and choices

## Office for Human Rights

Department of Developmental Services – Office for Human Rights  
500 Harrison Avenue  
Boston Ma 02118

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**Richard Santucci, Director of Human Rights**

**Phone: 617-624-7738**

**[Rich.Santucci@massmail.state.ma.us](mailto:Rich.Santucci@massmail.state.ma.us)**

To oversee a system of safeguards which affirms, promotes and protects the human and civil rights of the people the Department supports



# LIMITATIONS

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Why and how

## IMPORTANT CONCEPTS

- **Least restrictive** –Use the minimum limitation on individual freedom that will still insure safety from unreasonable risk.
- **Unreasonable risk** –It will vary for each person and each situation. Use a team process to assess risk and consider alternatives.



## People have a right to experience reasonable risks

### A reasonable risk

Eileen is a bit overweight and is trying to eat healthier foods. Her doctor recommended that she try to lose 25 pounds. She came home from a walk on Saturday with a box of donuts and started to eat them. Supporters remind her that the donuts are high in calories and will cause her to gain weight. They suggest healthier options instead. When Eileen has her 'weigh in' at the Weight Watchers meeting later that week, she finds that she has gained three pounds.

### An unreasonable risk

☞ Janet has diabetes. She came home from a walk on Saturday with a box of donuts and started to eat them. The last time this happened, she went into a diabetic coma.

## Reasonable vs Unreasonable Risk

### A reasonable risk

☞ Bernie lives in a community residence and can generally go into the community by himself for a few hours. On Friday night, he wants to go to a local bar for karaoke night by himself. Supporters are afraid; they are just not sure what will happen. Perhaps the patrons at the bar will make fun of him or take advantage of him in some way. Bernie says he will only bring enough money to buy 2 beers, and will carry his cell phone in case of emergency.

### An unreasonable risk

☞ Becky tells staff that her boyfriend is coming to pick her up at the house. When he arrives in his car, he is driving erratically and when he comes to the door, he smells of alcohol. Supporters don't want her to get into the car with him.

## THE PROCESS FOR LIMITATIONS

1. **A compelling reason** must exist for this limitation. There must be a element of **imminent risk** to the person or to others.
2. **The proposed limitation** must be the **least restrictive** method possible to reduce or eliminate the risk.
3. The individual/guardian has to give **consent**.
4. There has to be a **teaching plan** for the person so that they will be able to learn what they need in order to be free from the limitation. This includes criteria to fade or end the restriction.
5. The proposed limitation plan is **reviewed** by the ISP team and the provider's Human Rights Committee.

## Case Example

- ☞ **Compelling reason** - Julie wants to use the stove by herself to cook lunch. However, she has burned herself on three occasions and last week, she started a small grease fire in the kitchen.
- ☞ **Proposed limitation** – Julie can only use the stove with supervision
- ☞ **Less restrictive alternatives** – staff have explained how to use the stove and showed Julie how to cook some of her favorite items. However, she has continued to have cooking accidents
- ☞ **Consent** – Julie and her guardian agree
- ☞ **Teaching plan** – staff will work with Julie every Saturday afternoon on cooking. They will use colored tape on the stove dial to indicate how high to turn up the burner. They will provide less support over time as Julie becomes more proficient. They will take progress notes on how much assistance she needs each time.
- ☞ **Plan to fade** – After 6 months, the team, including Julie and her guardian, will reassess Julie's ability, review progress notes and determine whether she is safe to cook independently.

## Human Rights Advisory Council

- 15 members from various parts of MA
- Membership
  - People with intellectual disabilities
  - Family members and guardians
  - Professionals
  - Legal and disability advocacy organizations
  - Service providers
- Meet monthly and on special projects

## Human Rights Advisory Committee

To advise the DDS Commissioner on the affirmation, promotion, protection, and monitoring of the human and civil rights of individuals served by the Department

- Review and report on Human Rights policies and regulations
- Support the work of the Human Rights office
- Consider current content for Human Rights trainings
- Assist local DDS Human Rights committees
- Work with various disability organizations




# Human Rights Advisory Council


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Human Rights Resources for Families

4/28/2016



The Department of Developmental Services  
Elin Howe – Commissioner  
Richard Santucci – Director of Human Rights  
Human Rights Advisory Committee  
500 Harrison Ave  
Boston Ma 02118



# Human Rights Advisory Council

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## Rights Review Newsletter

### Rights Review

Promoting Human Rights by providing information and discussion across DDS

Newsletter of the DDS Human Rights Advisory Committee  
and the DDS Office for Human Rights

Volume 6 Issue 1 August 2016

Getting Connected

Supporting the human rights of more than 36,000 people served by the Department of Developmental Services is a big job and a crucial one. There are a number of parts to play, all important. A lot of the work falls to the provider support Human Rights Committees. There are 140 provider agencies, and many have more than one committee. These committees are asked to protect the rights of some of our most vulnerable people. Review, support, and plans can be complicated and difficult to implement and to review. The office for Human Rights and the Human Rights Advisory Committee would like to help.

This issue of the Rights Review is our effort to introduce (or re-introduce) ourselves to the community of Human Rights Committee members, Human Rights Coordinators, advocates and self-advocates. We would like to offer ideas, guidance, and updates. We hope that you will offer suggestions, let us know how we can help, and share your thoughts, questions, comments, and questions to please:

• Share this newsletter with others.

Human Rights Champion

John worked in his work program one day last year and his supporters noticed that he was not his usual self. They were concerned and advised if he was feeling ok. John discovered that he was having some difficulties at home, he did not feel that he was being treated well. The agency's Human Rights Coordinator and their Human Rights Committee felt that something needed to be done to support John.

They contacted the DDS regional Human Rights Specialist and asked her to look into the matter. She met with John, who expressed his desire to move out of his



# Solving Human Rights Issues



What can a family do?

## CONCERNS ABOUT THE QUALITY OF SERVICES

There may be instances, in which services for your family member are **just not satisfactory**.

- Staff may not be attentive and respectful
- The services might seem too restrictive
- The services may not be sufficient to meet their needs
- The provider may not be doing what was agreed to

Your family member deserves great services and you can advocate for them.





## CONCERNS ABOUT THE SERVICE PROVIDER

**If you are not satisfied with the way in which services are being provided:**

- Start with the **Service Coordinator**.
- Contact the **provider agency management staff**. They may not be fully aware of program issues.
- Contact the **area office**. They fund the provider agency. They have a responsibility to make sure that the provider is doing what they are supposed to.
- File a grievance with the provider agency **human rights committee**. You can access the committee through the provider's human rights officers or coordinator.
- Contact your Regional **DDS Human Rights Specialist** or the DDS Director of Human Rights. The Office for Human Rights can offer guidance and support.

- Use the Individual Support Plan (ISP) meeting to discuss the goals and challenges of your family member and the services that they need to succeed.
- You may want to advocate for additional services or a different provider.
- If you are not in agreement with the service plan you have **the right to appeal the ISP to the DDS Regional Director**.
- You can request an ISP modification meeting if you don't want to wait until the next regular ISP meeting is scheduled.

## REPORTING ABUSE AND NEGLECT

### What to do if you suspect abuse or neglect by a caregiver:

- Call the **DPPC (Disabled Persons Protection Commission) 24-Hour hotline at 1-800-426-9009.**
- The standard for reporting suspected abuse and neglect to the DPPC is "reasonable cause to believe," that abuse, neglect or mistreatment was committed against a person with a disability. You don't need to be 100% sure. When in doubt, make the call and let the investigators decide.
- Everyone who works with individuals with disabilities are mandated reporters. Non-mandated reporters can call DPPC too.

## OUTCOMES

- The provider is immediately notified of any allegations against its employees and is required to take all necessary **immediate action to protect** the alleged victim, pending the outcome of the investigation.
- A **written report** of the investigation's outcome will be sent to **Individuals or their Guardians upon request** with instructions for **appealing that outcome**, in case they do not agree with it.
- **The guardian would have to call DPPC to find out when the investigation is completed in order to make the request.**

## Mass. Families Organizing For Change

A statewide, grassroots coalition dedicated to individual and family support



Our vision is one of empowerr  
individual and family support  
planning, choices and decisio

<http://www.mfofc.org>

## Mass Families Organizing for Change (MFOFC)

- Imagine Better!
- MFOFC offers advocacy boot camps, leadership development, workshops, trainings and conferences to parents, guardians, siblings, and caregivers
- Families are the driving force behind policies and practices that promote dignity and better lives for people with disabilities.
- Encourage your loved ones to speak up and advocate for themselves

## MAKING A POSITIVE IMPACT



You can help

## GET INVOLVED

- Get to know the provider and DDS staff that work with your family member. **Communicate regularly** and visit as often as you can.
- **Help the provider to really know your family member.** You are the expert on your family member.
- **Help the staff to know about their preferences, interests, needs, and accomplishments.** They are not just a service recipient, they are a **person**.
- Help your family member to celebrate **their religious and cultural heritage**. It is an important part of who they are.

## SPEAKING UP

- You are a part of the service team
- You have something to offer
- If you see something you don't like – **SPEAK UP**
- If you have an idea or suggestion – **SAY IT**
- If things are going well – **LET THEM KNOW** (this will encourage them to keep it up)



## THE SKY IS THE LIMIT



## DDS RESOURCES

- **DDS Office for Human Rights** - Richard Santucci, Director 617-624-7738  
[Rich.santucci@state.ma.us](mailto:Rich.santucci@state.ma.us)
- <http://www.mass.gov/eohhs/consumer/disability-services/services-by-type/intellectual-disability/newsroom/about/major-dept/deputy-commish/developmental-services-human-rights-office.html>
- **DDS regulations and policies**  
<http://www.mass.gov/eohhs/gov/laws-regs/dds/>

- **Disability Law Center** <http://www.dlc-ma.org/>  
Phone: (617) 723-8455
- **Massachusetts Families Organizing for Change**  
<http://www.mfofc.org/> Phone: 508-824-6946
- **The ARC of Massachusetts**  
<http://thearcofmass.org/> Phone: (781) 891-6270
- **Disabled Persons Protection Commission**  
<http://www.mass.gov/dppc/> Phone: **800-426-9009**

# Thank you



Training produced by the Center for Developmental Disabilities  
Evaluation and Research (CDDER) [cdder@umassmed.edu](mailto:cdder@umassmed.edu)