



Department of Developmental Services

Human Rights Officer

Handbook



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**Our lives
begin to end
the day we
become silent
about things
that matter.**

-Martin Luther King Jr.

What is Human Rights Advocacy?

Advocating for human rights means taking a stand to improve a situation by speaking out on human rights issues. When supporting adults with intellectual and developmental disabilities, it is important to educate and empower each person to speak up for themselves. As advocates, we must ensure that the people we support understand the following:

- Everyone should be treated equally.
- Everyone should be treated with respect and dignity.
- Human rights are the same for everyone.
- Everyone should know their rights and how to exercise them.
- Everyone should have choices and opportunities to choose.
- Everyone should be supported to make their own decisions.

Why do we need Human Rights Officers?

In our field, Human Rights Officers work to promote and protect the human rights of those who find it difficult to speak up for themselves. Officers support these individuals to understand their rights, get their voices heard and get their needs met. With the support of Human Rights Officers, people with intellectual and developmental disabilities can become educated and empowered to improve their own qualities of life by speaking up for themselves and taking action to get what is important to them.

Characteristics of a Good Advocate

Objective

Independent

Resourceful

Assertive

PERSISTENT

Patient

Good Listener

Sensitive

Trustworthy

CONSIDERATE

Duties of the Human Rights Officer

1. Participate in training.
2. Assist provider agency in developing the means to promote the human & civil rights of the individuals served.
3. Inform staff, individuals & families/guardians of the individual's rights.
4. Annually train and assist individuals to exercise their human rights.
5. Document annual trainings.
6. Inform individuals of grievance procedures & their right to be heard by the Human Rights Committee.
7. Assist individuals in obtaining legal advice or representation by providing legal information and/or referral (with technical assistance from DDS).

Duty 1: Get Trained!

Take advantage of any training opportunities, which might inspire and help you to be a better advocate:

- DDS offers trainings in each region. Trainings are outlined and described in each region's "learning calendar," which you can find on www.ddslearning.com
- Visit www.ddslearning.com for additional training opportunities. Topics include:
 - Trauma Informed Care
 - PBS
 - Self-determination
 - Mandated Reporting
- YouTube is a great place to search and view videos related to human rights and advocacy.
- Google can direct you to links, news articles, images, and videos on any topic.
- Conferences are a great way to meet new people, network and learn what others are doing to provide high-quality services and supports to people with intellectual and developmental disability. Find out about:
 - The Self-Advocacy Conference
 - The Shared-Living Conference
 - The MassMobility Conference
 - The Human Rights Forum
- The DDS Regulations outline what is expected of funded service providers who support people with intellectual or developmental disabilities, brain injury and autism. Chapter 5 of the regulations outline the "Standards to Promote Dignity." These standards include human rights.

Duty 2: Promote Human Rights within My Agency

- Share what you've learned in training.
- Start a newsletter for staff of your program site.
- Contribute to the existing agency newsletter or webpage.
- Prompt a discussion during a staff meeting.
- Organize a "house" meeting to discuss topics with the people you support.
- Share a video.
- Create a role play exercise.
- Brainstorm a scenario.
- Organize a Human Rights Trivia game

Duties 3, 4 and 5: Teach Human Rights

- Know Chapter 5.03 and 5.04 of the regulations
- Be able to answer questions about rights.
- Know who you can go to for support/guidance.
 - Human Rights Coordinator
 - Human Rights Specialist
- Understand the needs of your audience.
- Make it relevant.
- Break it down.
- Make it interactive.

Duty 6 & 7: Address Complaints and Help a Person to Speak Up

A complaint can be swiftly addressed and resolved in-house with action on the part of the Human Rights Officer, Human Rights Coordinator, and the agency as a whole.

There may, however, be an occasion when a complaint is not able to be resolved in this manner and requires an alternative response.

The agency should have a formal grievance procedure for any person receiving services who wishes to make a complaint. As the Human Rights Officer, you must understand this grievance procedure and be able to help the people you support to utilize it if necessary.

Ask for help if you need it. The agency's Human Rights Coordinator and the DDS Human Rights Specialist are always available to answer your questions, and to help you address human rights issues. Should a human rights complaint escalate to the level at which legal intervention is necessary, you should also know which legal resources are available.



The Disability Law Center is the official protection and advocacy agency for people in Massachusetts who have disabilities. Call (617) 723-8455 if someone you support is in need of legal assistance.

What Are Human Rights?

In our field, when we talk about “human rights,” we are referring to the way in which people receiving DDS services are treated by their caregivers. As Human Rights Officers we must work to promote and protect the following:

- Equality
- Freedom of Choice
- Self-Determination
- Dignity

Unfortunately, people with disabilities were not considered valued members of society. They were segregated and excluded. They were denied access to things like employment, education and healthcare. They endured decades of poor treatment in institutional facilities.

- Treated like animals or sub-humans
- No privacy
- Warehousing & overcrowding
- Denial of preventative medical/dental care
- Involuntary sterilization
- Experiments using radioactive material
- Rampant abuse and neglect
- Confinement

It’s important to be aware of and never forget what we have learned from history.

Fortunately, as a result of increased awareness and strong advocacy, there have been many positive changes. DDS’s guiding principles include promoting the dignity of each individual, freedom from abuse or neglect and empowering individuals and their families to speak out for themselves and others, initiate ideas, have choices and make decisions about supports;

Chapter 5 of the DDS Regulations is titled “Standards to Promote Dignity.” In sections 5.03 and 5.04 of this chapter, you will find a list of general principles and expectations for protecting, promoting, and affirming the rights, dignity and self-determination of people served. You will want to familiarize yourself with these regulations and know where to find them for reference.

The full regulations can be found on our DDS website at:

<https://www.mass.gov/lists/dds-regulations>

What do the DDS Regulations say about human rights?

According to the DDS Regulations, we all have the right to make decisions about our lives. We also have the right to basic goods, services & opportunities to improve the quality of our lives.

What does it mean to “teach human rights?”

One of your duties is to teach human rights to the individuals you support. You can do this in a variety of ways, but the goal is to help the individuals you support to understand what their rights are and how to exercise them. The best way to accomplish this is to explain each right while simultaneously involving the person in an activity, which allows them to experience how others express that right. For example, accompanying someone to a town hall meeting or a debate will allow them to experience how others exercise the right to expression.

How do we balance rights and responsibilities?

As members of society, we have both rights and responsibilities. Responsibilities are built into the idea of rights. Rights are founded upon the expectation that we have the right to be treated fairly and respectfully by others AND that we are doing our part to respect the rights of others. We also have a responsibility for our own wellness.

At the end of this handbook you’ll find a list of suggested activities to help you teach others about human rights.

Services and Supports

Services and supports are designed to provide meaningful assistance to the person in acquiring skills which enable them to cope with the demands of their own person and environment. All services and supports should be explained to the person so that they understand what's going on. Services and supports promote:

- Dignity
- Respect
- Self-determination
- Freedom of choice

Home

The person's home should:

- Be a place where they feel safe.
- Be comfortable and decorated with items which reflect the person's interests, preferences, culture, and background.
- Be part of their preferred community.
- The person should choose to live there.

Community

The person should:

- Be familiar with their community.
- Be able to readily access the community.
- Be a member of the community.
- Have opportunities to meet other people (with and without disabilities) living in the community.
- Have opportunities to meet other people with similar interests.

Leisure Activities

The person should:

- Be able to participate in activities they like.
- Have opportunities for exercise and fun each day.
- The person should have the opportunity to undergo typical developmental experiences, even though such experiences may entail an element of risk; provided however, that the individual's safety and well-being shall not be unreasonably jeopardized.

Clothing/Appearance

- What the person wears is their choice.
- The person should shop for their own clothing.
- Caregivers should support the person to make sure their clothing is always neat and clean.
- The person should have clothes for every season.

Possessions

- If the person buys something with their own money, then it's theirs to use when and as they please.
- A person's personal possessions cannot be restricted unless they are using the possession illegally or in a manner which jeopardizes their or someone else's safety.
- If restrictions are necessary, then there is a process, which must be followed.

Communication

The person should:

- Always be able to contact the people they want to talk to
- Have privacy whenever they are using the phone, texting, sending email, using social media or any other form of communication.
- Get the assistance/accommodations they need to communicate effectively with others.

Expression

A person has the right to think and say what they want. A person also has the right to engage in activities, which reflect their own personal feelings, beliefs, and interests.

Includes:

- Religion
- Politics/Voting
- Fashion
- Music
- Home Décor

Privacy

The state of being free from public attention. This includes:

- Private space.
- Privacy when visiting with others.
- Protection of private information.
- Privacy when communicating with others.
- Privacy and control of the body.

Private Space

A person should:

- Have privacy when sleeping.

- Have privacy when using the restroom or tending to hygiene.
- Have private space to converse with visitors.

Private Information

- A person's picture should never be posted online or in any place outside of their home unless consent has been given by the person or their guardian.
- A person's private information should never be shared without consent from the person or their guardian.
- A person's identity should be protected during conversations.

Privacy and Control of the Body

A person should:

- Feel comfortable with the gender of the staff person who is assisting with hygiene activities.

If a person is uncomfortable with the gender of the staff who is assisting with hygiene, then someone else should step in to help or an alternative option for completing the task should be given.

Association/Visitation

The person should:

- Be able to choose their own friends.
- Be able to have visitors in their home.
- Have privacy when visitors arrive.

- Be able to entertain visitors in their bedroom.

What about sex?

- Sex is natural.
- People experience sex in different ways and should be supported to understand the risks associated with sexual activity.
- A person should be supported have safe and healthy sexual experiences.
- Sexual preference is personal and private.
- Sex must be safe.

Health

A person should:

- Have a primary care physician they prefer.
- Have access to a medical specialist if necessary for condition-specific health care needs.
- Have ongoing health maintenance.
- Be involved in the process of making health-care decisions to the extent possible.
- Be informed of all health-care issues & options to the extent possible.

Nutrition

The person should:

- Have kitchen cabinets and a refrigerator full of nutritious foods.
- Help with the grocery shopping so that they can buy the foods and drinks they like.
- Be encouraged to make healthy choices and offered healthy alternatives but they should be able to eat what they want.

What about a doctor's order?

- The person can choose whether to follow the doctor's advice.
- If a doctor makes a recommendation the person doesn't agree with, then we must:
 - Advocate for what the person wants.
 - Advocate for safety.
 - Discuss the issue with the ISP team to come up with a solution.

Safety

The person should:

- Feel safe at home.
- Feel safe at work.
- Feel safe in the community.
- Know what to do if feeling unsafe.
- Be supported to understand risks/safety concerns they may potentially encounter.

Due Process

A person has the right to:

- Know what is included in their personal file.
- Review plans, policies, and protocols regarding their own treatment.
- Be involved in the ISP process and attend the meeting.
- Request a modification of their ISP or plan.
- Decline services, treatment, or other support.
- File a grievance with the Human Rights Committee.
- Contest their own guardianship.

Things to Consider When Teaching Human Rights

When teaching rights to the people we support, it is important to:

- Consider the memory and retention challenges some people face!
- Remember that too much information all at once can be overwhelming.
- Use clear and concise language!
- Provide examples of ways to exercise each right!
- Get people involved in activities which allow them to experience what it feels like to exercise their rights!
- Make the training interesting!

Rights and Risk

There are times when it may be necessary to restrict a person's movement, access, and privacy. These are times when the circumstances involve a risk to the person or others.

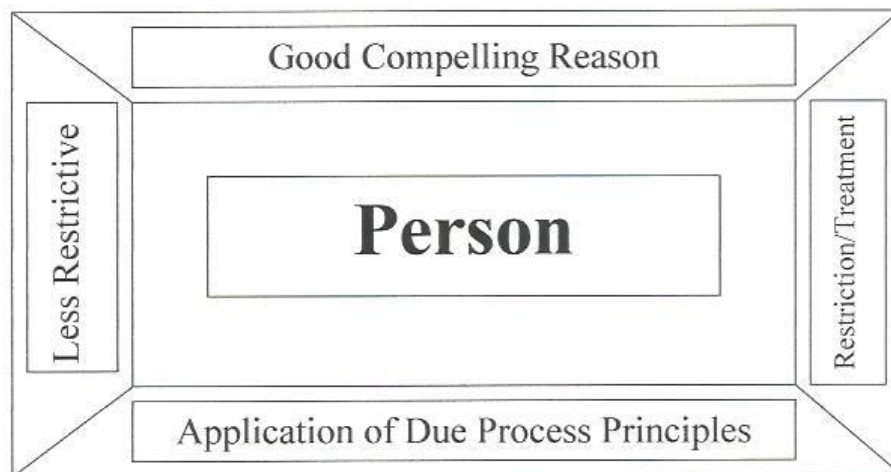
Examples:

- Locking sharps if person has threatened to stab someone or hurt himself.
- Locking food cabinets for a person with Prader Willi syndrome who cannot control the desire to eat.
- Using a seat-belt guard for someone who repeatedly removes their seatbelt while the vehicle is in motion and attempts to grab the driver.
- Monitoring internet use for a person who attempts to access child pornography.

If a restriction on rights is warranted, then the team must follow the **Human Rights Framework** to ensure the least-restrictive intervention is used and that the team agrees the intervention is appropriate.

A written plan outlining the use of the restriction must be agreed to by the team.

The Human Rights Framework



Put the person & your knowledge of them in the center of planning:

- Who is this person and why are they placing themselves or others at risk?
- Are there changes occurring to cause these risks?
- Are there environmental concerns leading to this?
- What can we do to better serve their needs?

Check the scene

If there are restrictive practices and devices being utilized at your program site, then find out whether the framework was used to process them.

Ask:

- Is there a good and compelling reason for this restriction?
- Is it the least restrictive thing we could've used?
- Which skills are we teaching the person, so that we can eliminate this restrictive practice in the future?
- Have we explained the restriction to the person and gotten consent from the person/guardian?

	Best Practices	
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- Get to know the participants in your program.
- Establish natural relationships with persons in your program, which will allow you to observe and know their preferences and tendencies and what may upset them.
- Be a source of information about where things are going well and where they may need improvement.
- Be sure to implement all plans, protocols, and procedures as written.
- If you see others implementing these differently, then you should get this clear
- Providing good habilitative care and treatment is everyone's responsibility. Everyone should be on the same page to ensure all plans and protocols are successfully implemented.
- Help people find ways to exercise their human rights.
- Promote self-determination in even the smallest tasks.
- Provide choices.
- Help people to make meaningful decisions.
- Help people find opportunities to speak up.
- Help people with challenging situations through discussion, pictures, role-modeling, and role-playing.

Activities

The following is a list of activity options, which can help to teach the people you support how to exercise their human rights:

Right	Activity
Services & Supports	Help the person to review and understand their Individual Support Plan. Verify that the person's vision and goals are accurate. Explain the modification process and how it has been utilized by others.
Home	Browse through home décor magazines and help the person to identify desired items. Assist the person to decorate their room according to their preference.
Community	Take a walk with the person around the neighborhood. Identify places of interest and assist the person to access them. Help the person to greet and introduce themselves to neighbors and other community members (if the person wants to do this).
Leisure Activities	Assist the person to browse the newspaper or online for activities of interest. Help the person to schedule and attend preferred activities.
Clothing/Personal Appearance	Go to a clothing store and assist the person to try on different clothing items. Assist the person to purchase preferred clothing items. If possible, help the person to identify a preferred style and to purchase other items, which reflect this style.
Possessions	Help folks inventory their own stuff and help them to find more stuff.
Nutrition	Take a walk with the person through the produce section of the grocery store. Purchase a new vegetable and help the person to use it to prepare a healthy dinner.
Communication	Assist the person to call or write to a family member or friend.
Privacy	Discuss good touch/bad touch and how folks should not be touched without consent even if it is an "appropriate" touch.
Association	Assist the person to visit a family member or a friend.
Health	Discuss the importance of good health and well-being. Take a yoga class or try yoga at home.
Safety	Teach the person how to use a crosswalk safely.
Expression	Watch and discuss a debate on television.
Due Process	Review and discuss the person's behavior plan or treatment plan. Explain the rationale for the plan and each intervention. Inform the person of the process for modifying the plan, if necessary. Review and discuss the agency grievance procedure.

Scenarios

David purchased an iPad with his own money. He is a gentleman who when he gets angry, will swear, threaten, and sometimes punch people. He uses the iPad to access the internet, play games and video chat with his friends. In order to use his iPad, David must be free of all verbal and physical aggression. With this incentive in place, things have gotten better.

Is this okay? What alternatives could we find?

Cassandra works at Dunkin Donuts. Jason, a customer, asks Cassandra if she would like to go to the movies with him. Cassandra tells Jason that she would love to go but doesn't think her staff will approve. Jason contacts the agency asking for help.

Do you think Cassandra should be supported to go on a date with Jason?
What needs to be considered with respect to Cassandra's safety and wellbeing?

Sue, a 26-year old woman comes to you and says that her rights were violated. She reports that she does not agree with her Positive Behavior Support Plan and wants to talk to the Human Rights Committee about it. She specifically wants to complain to the committee about staff hurting her during holds and said that one staff pulled her hair during a hold this morning.

What do you do?

Javier, a gentleman who attends the day program where you work, comes to you, and says he needs a lawyer. He wants to terminate his guardianship and to be able to make decisions for himself. He feels that his team is not supporting him to do this and wants to consult a legal expert.

Who would you talk to? What steps might the team take?

Carline, a 53-year-old female, has an ISP meeting coming up. For the last five years she has refused to attend her meetings and has said that “no one ever listens to me there anyway.”

What do you do?

Heather uses obscene language and derogatory words when she is angry. She has used the N-word multiple times in public. You have heard the staff tell Heather that she cannot use that type of language and threaten to take her cell phone away if she continues.

What do you think?

Matt hangs a poster of a nude woman on the wall in his bedroom. A few staff are offended by the poster and complain. Matt's mother is his guardian. She is also offended by the poster and asks for it to be removed. Matt refuses to remove the poster and asks for your help.

What do you do?

Ken, a gentleman you support, has all of a sudden become incontinent of urine each night. You believe there is a physiological cause, but the Ken's doctor argues that it's a "behavior problem," and wants you to come back in 6 months for follow-up.

What do you do?

Resources and Support

Get to know your agency's **Human Rights Coordinator**. The Human Rights Coordinator can help you to navigate human rights complaints and to address concerns brought forth by the people you support, their family members and others. The Human Rights Coordinator should always be kept abreast of human rights issues, as they inform the Human Rights Committee of these issues.

Your agency's Human Rights Coordinator is: _____

Get to know your region's **Human Rights Specialist**. The Human Rights Specialist works for the Department of Developmental Services and can also help you to navigate human rights concerns and complaints.

Office of Human Rights Contact Information:

<p>Director of Human Rights Joseph Weru: 617-939-1867 Joseph.W.Weru@mass.gov OfficeOfHumanRights@mass.gov</p>	
Human Rights Specialist	Phone#
<p>Central/West Region <i>Leo Luczynski-Badia</i> Leonardo.Luczynski-Badia@mass.gov</p>	413-544-9009
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<p>Metro Region <i>Amy Boone</i> Amy.Boone@mass.gov</p>	413-386-3403