



SAFEGUARDING HUMAN RIGHTS

THE ROLE OF FAMILIES AND GUARDIANS



Elin M. Howe, Commissioner

Tom Anzer
Director for Human Rights

Human Rights Advisory Committee

The Department of Developmental
Services

500 Harrison Avenue
Boston, Massachusetts 02118

The Role of Families and Guardians In Safeguarding Human Rights

Purpose: To inform family members and guardians about the human rights of persons supported by the Department of Developmental Services (DDS) and how they can participate in the system safeguarding those rights.



I. The Human Rights of Individuals supported by the DDS.¹

Three key principles guide this policy.

1. Respect for every individual.
2. Education and support for every individual and his/her supporters in understanding the individual's rights and the need for consideration of the rights of others.
3. Respect for the freedom and the power of individuals to express their wishes and to expect their choices to be respected. For those individuals who have difficulty with such expression, their supporters/guardians should strive to understand and convey the wishes of the person that maximizes the individual's choice, human rights and dignity.

Rights Enumerated:

1. **Dignity:** the right to be treated with respect for the unique gifts of each person, including respect for ethnic and cultural diversity.
2. **Self-determination:** the right and opportunity to make meaningful choices and informed decisions. Informed decision-making includes the right to decide to take reasonable risks. Supporters must help the person understand and weigh the risks and benefits of their decisions, as needed.
3. **Personal Safety:** the right to be safe and free from harm or abuse.
4. **Competent Treatment and Training:** the right to appropriate supports and competent treatment. This includes education and clinical supports that enable the person to learn, change and minimize need for interventions that have an impact on their rights.

¹ Adapted from the DDS Human Rights Policy

5. **Communication:** the right to communicate freely with others and to have support to communicate. This may involve access to personal and telephone communication, postal services, alternative hearing/communication devices, adaptive equipment, and reasonable assistance in using a relay telephone, or video systems.
6. **Relationships:** the right to visit others and to receive visitors, including the right to have friendships and intimate relations with mutually consenting adults.
7. **Privacy:** the right to privacy, which includes privacy during care of personal needs, in communication, in visits, in one's home and personal space, and confidentiality of personal information.
8. **Personal Property:** the right to obtain, keep, use, and dispose of personal possessions.
9. **Education, Employment, and Compensation:** the right to equal access to opportunities for education and employment. Individuals who are employed have the right to be fairly compensated for the work that they do.
10. **Community Membership and Access:** the right to services and supports that promote the individual's ability to live in the most typical and least restrictive settings appropriate to them and encourage ongoing, meaningful community access and involvement.

These rights may *not be altered except* for a proven compelling reason and through the procedural safeguards in DDS regulations.



II. Involving guardians and families in supporting and safeguarding human rights:

Principles for involving *guardians* in safeguarding human rights:

1. Guardians actively advocate for the best interest of the incapacitated person (legal title for adults under guardianship) for whom they have been named guardian. This means the guardian will be called upon to make important decisions that will affect the life of the person for whom they are guardian.
2. Guardians are vital members of the individual's Individual Support Plan team and are appointed by the court to act on the person's behalf, respecting self-determination whenever possible and helping the

- individual understand when and why his/her wishes may not be able to be honored in every instance.
3. The guardian is a member of the ISP team and is a partner in the ISP process. The DDS Service Coordinator is responsible for facilitating the ISP process and assuring there is a comprehensive review of the individual's Vision Statement, the assessed needs of the individual, and recording the goals and objectives for the future. If the guardian is not satisfied with the outcome of the ISP meeting, the guardian may appeal the ISP on behalf of the individual.
 4. ***Guardians should understand the limits to the authority granted by the court in the specific provisions of their order.*** For example, some guardianships may be temporary and some may be limited to medical treatment issues only. Guardians need to understand and respect the scope of their authority.
 5. Certain ***extraordinary medical and behavioral treatment procedures require specific court review and can not be approved by a guardian alone.*** These include treatment with antipsychotic medication, intrusive elective surgeries and end of life medical treatment decisions among others. When these issues are brought to court by a guardian, the ISP Team, or Rogers guardian, a judge must "substitute" his or her judgment for that of the incapacitated person.
 6. Where a person subject to guardianship is able to express their wishes on certain matters and decisions, ***guardians should consider deferring to the expressed wishes of this person,*** when possible and appropriate. If the person expresses a wish different than the ISP team, including their guardian, they have the right to continue to pursue their views in an ISP appeal, and have the right to be properly supported in this. If the guardian and the individual differ in their wish to appeal the ISP, the human rights specialist should be contacted.
 7. If a guardian questions whether the individual continues to need a guardian, the guardian should raise this possibility with the team.
 8. All ISP team members, including the guardian and the individual, have a role in developing any restrictions of the rights of the individual. Such restriction (e.g., visitation, communications, community access, privacy and control over possessions, etc.) must be reviewed and evaluated by the ISP team and are subject to Human Rights Committee review and if applicable, psychology Peer Review.

9. Guardianship is terminated at the death of the individual. If a family wishes access to information about the deceased, they must petition the Probate Court to be named personal representative.
10. Any guardian who believes that the person whose decisions they support has been subject to abuse or neglect should report that event to the Disabled Person's Protection Commission at 1-800-426-9009. If they have any questions about this, they may discuss this with the Human Rights Specialist for the Region (see page 7).

Principles for involving *family members* in safeguarding human rights:

1. Family members who are not guardians often remain involved in their loved one's life and may be informed, active members of the DDS Individual Support Plan (ISP) team. However, the person may choose to include some family members, but not others, or may choose not to include any of their family members on their team, and this choice will be respected by DDS and the ISP team.
2. Family members who are chosen to be involved in and informed about events in a person's life and be given contact information for those responsible for safeguarding their family member's rights
3. Any family member who believes their loved one has been subjected to abuse or neglect should report their concern and information to the Disabled Person's Protection Commission at 1-800-426-9009. If they have questions about this, they may discuss this with their SC or the Human Rights Specialist for the Region (see page 7).

III. DDS Oversight of the System of Human Rights Safeguards:

The DDS Human Rights Advisory Committee advises the Commissioner on any policy issues affecting the human and civil rights of individuals supported by the Department. The Committee oversees training for individuals and family members regarding how they are taught their rights and provided with opportunities to exercise of those rights and advises the Director for Human Rights in the operation of the Office for Human Rights.

The Office for Human Rights provides direct oversight of the Human Rights System, including provision of training, technical assistance, and oversight of restraint practices. Each Human Rights Specialist also provides a form of ombudsperson's role to *assist* individuals, family members, provider and Department staff with resolving conflicts or disagreements regarding human

rights issues in a reasonable manner. In pursuit of this, they cannot coerce solutions, but may advocate within existing channels, such as the established DDS chain of command, guidance on the use of ISP and complaint procedures, or they may participate in informal conflict resolution discussions with the consent of the parties.

The human rights system in the provider community includes the following parties or groups:

1. **The Human Rights Coordinator:** is a critical role that coordinates the activities of the agency regarding human rights promotion and compliance. The person is staff to the human rights committee and acts as a liaison to the administration of the agency regarding all activities regarding the promotion, training of and exercise of human rights in the agency.
2. **The Human Rights Committee:** an appointed group of volunteers made up of advocates, family members, self-advocates, and often an attorney, behavioral clinician, and a doctor or nurse. This group reviews all categories of limitation of movement, approves or disapproves of intensive behavior support plans, reviews select incidents, reviews policies of the agency and is a party to all complaints in that agency.
3. **Human Rights Advocates (Officers):** are the eyes and ears of human rights on the local level. This can be any person “affiliated” with the agency, who is empowered to help address human rights issues they see, or are reported to them, within the agency. Any person supported by the agency has access to support and guidance in fulfilling the responsibilities of this role for themselves or to help others.

Role of the Human Rights Specialists: staff of the DDS Central Office for Human Rights who are assigned a region in which to provide the technical support, oversight and advocacy identified above. Any person can call the Human Rights Specialist for their region to seek help, guidance, or technical support around concerns they may have. ***All calls may be kept confidential if this is preferred.*** While the Office is accountable to the Commissioner for monitoring and oversight of all restraints, it does not generally replace the roles of others in DDS or the provider agencies, but promotes and advocates for consistency in the system on human rights issues on behalf of the persons we all support.

Specialists can be contacted by phone as follows:

Central/West Region Specialist: 413-205-0892
Northeast Region Specialist: 978-774-5000, ext. 528
Southeast Region Specialist: 508-866-8873
Metro Region Specialist: 781-788-5261

IV. OPTIONS FOR ACTION

Where to go and who to contact when human rights may be compromised

- 1. Abuse or neglect may exist** – If you have reason to believe abuse, neglect or other forms of mistreatment may exist, you should report the incident directly to the Disabled Persons Protection Commission, at 1-800-426-9009. If you are uncomfortable reporting this you should report it anyway! Please remember that retaliation against any person, in any form, for filing a complaint on behalf of any person, is strictly forbidden in regulations and there are serious penalties to anyone who violates this.
- 2. The dignity, privacy, or other rights issues may have been breached** – If you see, or hear from your family member or person you support as a guardian, about potential human rights irregularities or outright violations, you may want to contact a Human Rights Advocate/Officer at the location, or the agency’s Human Rights Coordinator, or the person’s DDS Service Coordinator, to discuss the problem. If you do not feel you have gotten a satisfactory explanation or solution, the DDS Human Rights Specialist assigned to your region could assist as well. They could also help you sort through your concern. If you believe the breach of rights has led to physical or emotional harm to the person, you should file an abuse complaint with DPPC.
- 3. A treatment controversy exists** – If you are confused or concerned by elements of a behavior support plan, or medication treatment plan, you should discuss your concerns first with the your SC. If you have continuing concerns you may also discuss these with the Human Rights Coordinator for the service agency.

Persons have the right to refuse treatment if resolution of concerns can’t be reached. This should not be done lightly and the person or their guardian should inform the service coordinator of their clear detailed concerns so they may be able to be addressed in an ISP Team

meeting. Please be aware that emergency restraints are not deemed treatment requiring consent. Any physiological or psychological risks specific to the person that could arise with use of emergency restraints should be raised with the ISP team. You may want to talk with the Human Rights Specialist about any of these issues to help you sort through your concerns from a regulatory perspective.

4. **A restriction of rights exists or is being proposed** - A restriction of visitation rights, possessions, or freedom of movement, etc., must be reviewed and recorded through the ISP process. Asking the DDS Service Coordinator for an ISP modification meeting, or a meeting to discuss the issue with the ISP team may be a path for resolving your concerns. Your Human Rights Specialist may be able to help you form your questions, or understand what is required for safeguarding the issue.

V. *Going beyond my family member's rights, how can I learn more to help promote human rights for all?*

- * **Training modules or video links on DDS Office for Human Rights page, found at mass.gov/dds "human rights" on top left column.**
- * **Conferences and forums on human rights (also on web page when scheduled)**
- * **Participation in your agency's local Human Rights Committee**
- * **Participation in the DDS Human Rights Advisory Committee.**
- * **Presentation by a Human Rights Specialist for your family group or area board.**

Want more? Contact: Tom Anzer, Director for Human Rights

DDS Central Office
500 Harrison Avenue
Boston, MA 02118

Or at 617-624-7738, or via e-mail at: Tom.C.Anzer@state.ma.us

This brochure is a product of the Massachusetts Department of Developmental Services, and developed by its Human Rights Advisory Committee in partnership with the Office for Human Rights.

May 27, 2014