Human Rights Resources for Families

11/17/2017

The Department of Developmental Services
Office of Human Rights
Human Rights Advisory Committee
500 Harrison Ave
Boston Ma 02118

Introduction

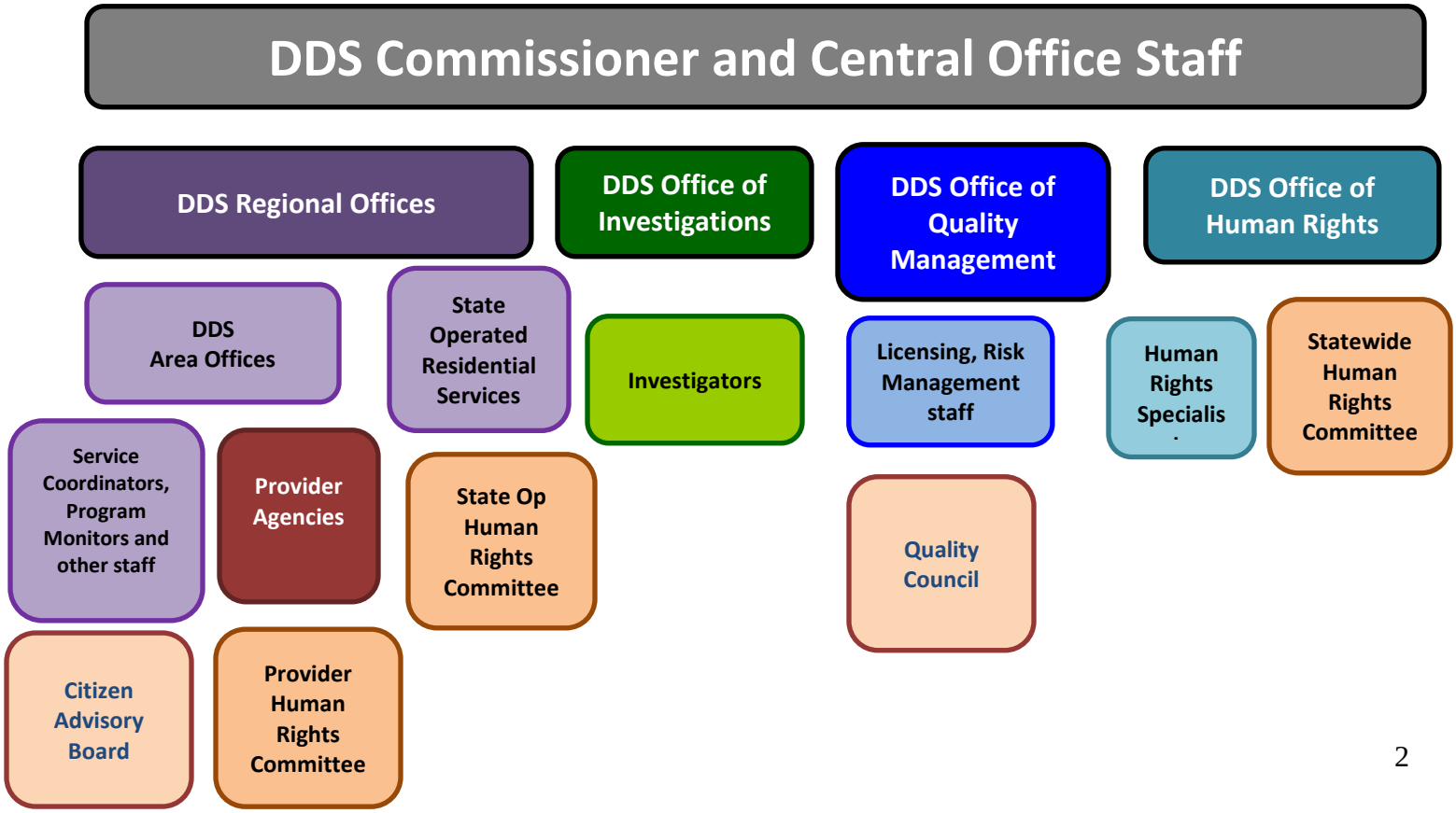
In developing this resource material, we tried to look at the basic information that a family member would need in order to be an effective advocate. We have included some basic information about how the Department of Developmental Services provides services. We focused on common human rights concerns, with suggestions about how to advocate for positive outcomes. It is important to remember that individuals do not just receive services, they participate in them. This includes important decisions about what the services are and how they are to be provided.

The Department of Developmental Services

The Department of Developmental Services (DDS) is dedicated to creating, in cooperation with others, genuine opportunities for individuals with intellectual disabilities to participate fully and meaningfully as valued members of their communities

The service system

- DDS provides specialized services to give individuals with intellectual disabilities supports that they need and opportunities to live the way they choose.
- Service recipients include approximately 38,000 individuals with developmental disabilities.
- Service types include day supports, employment supports, residential supports, family supports, respite, transportation, and other individuals support services.
- Services are provided through contracts with 235 private provider agencies, and through state operated services.
- Once eligible for DDS services, each individual is assigned a service coordinator at their local area office
- Usually, the area office contracts with a provider agency to provide support services for which the individual is eligible to receive, and which are agreed upon by the area office, the provider and the individual/guardian. This is a partnership between the individual/guardian, the DDS, and the provider.
- The provision of these services is monitored by a variety of sources within the department including area office staff, human rights staff, licensing staff, quality management staff, investigation staff, and citizen advisory boards and councils.
- Provider agencies are required to have human rights committees which provide oversight and monitoring.



Human Rights

The Department of Developmental Services has a system of safeguards to affirm, promote and protect the human and civil rights of the individuals whom it supports. These rights include the basic U.S. Constitution's rights provided for all people. In addition to this, there are Massachusetts General Laws and DDS regulations which provide additional systems of safeguards to insure that individuals receive the supports that they need, that they are free from mistreatment and are provided with opportunities for self-determination in their daily lives.

DDS System of Human Rights Safeguards

Every DDS and Provider Agency employee is responsible for treating each individual served with dignity and respect. They also must stop any abuse or mistreatment they witness, and are mandated to report such activity to the Disabled Persons' Protection Commission (DPPC).

Each Individual Service Plan (ISP) team includes the individual, guardian/family, their service coordinator, and provider agency staff. The ISP team determines the plan for services, including what will be provided and how they will be provided. This includes a review of any behavior support plan and restrictive procedures.

Human Rights Officers are appointed by Provider Agency Directors for each of their Agency service locations. These Officers are a point of contact for individuals and their families and can refer any human rights concerns/grievances to their agency Human Rights Committee.

A Human Rights Coordinator is an agency staff person assigned to provide oversight for the Provider Agency's Human Rights Officers, and to provide administrative support to the Provider Agency's Human Rights Committee.

The Human Rights Committee is an independent provider agency committee appointed in accordance with DDS regulations. These committees are charged protecting and affirming the rights of individuals, including the review and approval of behavior support plans, review of restraint orders, restrictive procedures, and investigations. They also provide advice to their agency director regarding the agency's policies and procedures.

DDS Human Rights Specialists are Regional staff members of the Office for Human Rights. They provide training, technical assistance and advocacy to all parts of the Provider and Departmental communities (including families, individuals, and human rights committees). The Human Rights Specialist assigned to each DDS Region is under the supervision of the Department of Developmental Services Director of Human Rights.

The Human Rights Advisory Committee (HRAC) represents all the constituencies of the Department and advises the **Commissioner** on significant human rights policies and concerns. HRAC ensures that individual rights are protected within the policies and practices of the Department.

http://www.mass.gov/eohhs/gov/laws-regs/dds/ - This is a link to the full DDS regulations as well as DDS policies and other information, including OHR newsletters, background & updated or current Human Rights information etc.

Department of Developmental Services
Office for Human Rights
Richard Santucci, Director of Human Rights
500 Harrison Avenue
Boston, MA 02118
Phone: (617) 624-7738

REGION	CONTACT INFORMATION	AREA OFFICES AND DEVELOPMENTAL CENTERS
Central/West	**Teka Harris** Human Rights Specialist DDS Central/ West Region 140 High Street Springfield, MA 01105 Phone: (413) 205-0892 1-(800) 328-3123, x0892	Berkshire, Franklin/Hampshire, Springfield/Westfield, Holyoke/Chicopee, South Valley *(Milford & Southbridge locations),* North Central, Worcester, Templeton Developmental Center
Northeast	**Rebecca Christie** Human Rights Specialist DDS Northeast Region Hogan Regional Center P.O. Box A Hathorne, MA 01937 Phone (978) 774-5000, x 528	Lowell, Merrimac Valley, North Shore, Metro North, Central Middlesex & Hogan Regional Center
Southeast	**Nate Hoover** Human Rights Specialist DDS Southeast Region 151 Campanelli Drive, Suite B Middleboro, MA 02346 Phone: (508) 866-8916	Brockton, Taunton/Attleboro, Fall River, New Bedford, Cape/Islands, Plymouth, South Coastal & Wrentham Developmental Center
Metro	**Jennifer Benoit** Human Rights Specialist DDS Metro Region 411 Waverley Oaks Road, Suite 304 Waltham, MA 02452 Phone (781)788-5261	Newton/South Norfolk, Middlesex West, Charles River West, Greater Boston

The Role of the Guardian

All adults, including those with developmental disabilities are presumed to be competent, and they maintain the legal rights to make decisions regarding health, education, finances and safety, unless a court determines that that are not able to do so. There is a range of decision making supports available which include full and partial guardianship, conservatorships, power of attorney, health care proxy, representative payee and other options. An appropriate choice of decision making support allows for individuals to get the assistance and protection that they need, while retaining as much authority over their lives as is possible.

Mass General Law chapter 190B, section 5-309 states:

- A guardian shall exercise authority only as necessitated by the incapacitated person's mental and adaptive limitations, and, to the extent possible, shall encourage the incapacitated person to participate in decisions, to act on his own behalf, and to develop or regain the capacity to manage personal affairs. A guardian, to the extent known, shall consider the expressed desires and personal values of the incapacitated person when making decisions, and shall otherwise act in the incapacitated person's best interest and exercise reasonable care, diligence, and prudence

Guardians therefore have to balance two important objectives:

- Insure that they know the individual and that decisions and choices are made in their best interest, to keep them safe, healthy, and free from unreasonable risk.
- Insure that individuals get to make decisions and choices about their own life that they are capable of making.

This can be a very difficult balance to strike. Each person and each situation is unique. Individuals, support staff, and guardians may have differing views about the need for the guardian to make decisions on behalf of the individual. Choices, including those made by guardians should also reflect the preferences of the individual. The best approach is to communicate directly and clearly about differences, remembering that all have the best interests of the individual at heart. The goal should be to honor the choices and preferences of the individual, even though they may not be what we would choose, provided there is not an unreasonable risk.

Behavior Support Plans and Restrictive Procedures

Individuals have rights to full access to their home, community, possessions and to have privacy. Under certain circumstances limitations may apply to these rights. This would only occur if the individual's safety and well-being are unreasonably jeopardized, if they &/or their guardian have consented to the limitation, and all of the required reviews and approvals have occurred.

DDS Regulations state that:

Individuals have ". . . [t]he opportunity to undergo typical developmental experiences, even though such experiences may entail an element of risk; provided … the individual's safety and well-being shall not be **unreasonably jeopardized**…" **Services should support Self-determination** & freedom of choice to the individual's fullest capability . . . "*(DDS Regulations, 115, CMR 5.03)*

Sometimes providers may need to balance the individual's right to exercise self-determination with the requirement to insure the individual's safety and well-being.

Any restrictive procedure requires a formal consent and a review process which includes:

- The proposed limitation is a response to an unreasonable health & welfare risk to the individual and others.
- The proposed limitation is the least restrictive intervention possible to maintain a reasonable safety measure.
- There is a teaching plan in place to reduce and/or eliminate a future need for the restriction
- There are specific criteria listed to fade or eliminate the restriction.
- The individual and/or their guardian have consented to the proposed restriction.
- The ISP team has reviewed the proposed restriction.
- The provider agency's human rights committee has reviewed the proposed restriction at least annually

Behavior support plans may be used to support the person in acquiring and maintaining those physical, mental, and social skills which enable the individual to cope most effectively with the demands of his or her own person and environment. A behavior support plan can be used when individuals have behaviors which put themselves or others at risk. A behavior support plan may also be used when individuals have behaviors which interfere with learning or with activities of daily life.

- The behavior support plan is considered to be "treatment"
- The plan identifies "target behaviors" which present risk or other significant issues for the individuals and others
- There is an analysis of what function the behavior serves for the individual
- The plan serves to reduce or eliminate the target behaviors while teaching more positive replacement behaviors that will take the place of the target behaviors
- Sometimes the plan will include restrictive elements, which must be the least restrictive possible
- There must be data kept to determine whether the plan is effective
- There is a specific criteria to fade or eliminate the plan
- The individual and/or their guardian have consented to the proposed plan.
- The ISP team has reviewed the proposed plan.
- The provider agency's human rights committee has reviewed the proposed plan
- Some plans will require additional clinical review

What is informed consent?

Informed consent is **an agreement** voluntarily given by an individual or guardian who understands and weighs risks and benefits involved in a particular decision. As individual/guardian, you have the right to give (or withhold) your consent to treatments such as medications and medical procedures, behavior plans, and restrictive procedures; you also can withdraw your consent at any time.

What you, as Family/Guardian can do, if you feel an individual is restricted in an unauthorized manner:

- Contact your provider agency staff & **discuss** your concern. They may be able to resolve it immediately.
- Contact your service coordinator or your area office supporting the individual. They may **facilitate a helpful discussion** with you and the provider.
- Speak with the Agency's Human Rights Officer or coordinator. If necessary, you can **file a grievance** with the Provider's Human Rights Committee by contacting their Human Rights Officer or Human Rights Coordinator.
- Contact the DDS Regional Human Rights Specialist or DDS Director of Human Rights. They can **explain** the regulations and the review/approval process.

Notification of Incidents to You from your Provider

The provider agency is required to inform the individual and guardian of all incidents resulting in any of the following: physical injury that requires any medical treatment, emotional harm, significant property destruction, police involvement, suspected mistreatment of the person, or staff use of an emergency restraint on the individual. This notification should occur within 24 hours of the incident.

Speaking up for your family member

Advocating for Services You Want:
Each individual receiving DDS services has an annual Individual Service Plan (ISP) meeting, and as a guardian, you are part of the Team planning. Other family members can be invited to participate in the meeting by the individual. The ISP meeting is very important for you for many reasons:

- **It allows** you as individual/guardian to share your vision for your life, which is the basis for the service plan and delivery.
- **It states** what services are currently provided and how they are carried out.
- **It reports** any assessment of the individual's abilities and needs, so the Team can make sure that ISP services address needs and expand abilities.
- **It provides** an opportunity for the individual or you to discuss concerns about current services As well as how they are provided. This is a good place to advocate for ISP changes you wish to happen.
- **It allows for changes** or additional services you want to happen.

Within 45 days of the ISP meeting you (the individual/guardian) will receive a written copy of the Service Plan to review, consent and sign. You have a right to consent or to appeal for changes. You may request Plan modification(s) before signing your consent. You should not wait until the next scheduled annual ISP meeting to convey concerns or request changes. If you do not agree with the ISP or items in it, you have a right to appeal to your Regional DDS Director. Simply not signing the ISP doesn't constitute a rejection or appeal.

Expressing your concerns about the quality of services and the human rights of your family member:

There may be instances, in which services are not provided as agreed to in the ISP, or do not comply with DDS regulations, or are just not satisfactory. Some people who receive DDS services cannot speak for themselves and need your help (as family, friend and advocate) to voice to their concerns.

All people have the following rights which you should know and advocate for if you feel they are not being honored and carried out:

- **Right to** "**humane and adequate care and treatment**". Staff members should be attentive to your family member. They should speak to him/her respectfully, calmly, and in an age appropriate manner. Activities (such as television or music …) should be based on individuals' interests rather than staff selection or preference.

- **Right to appropriate communication.** Staff should assure that communication devices and other methods & modes of communication used by your family member are provided and used by all staff members.

- **Right to freedom from discomfort, distress, and deprivation which arise from an unresponsive and inhumane environment**. Staff need to provide good and thorough personal care, so your family member is clean, comfortable and properly dressed. They should know the special support needs of each individual, which may include such things as communication method or device, specialized diet, medical &/or behavioral supports etc.

- **Right to self-determination and freedom of choice.** This includes such things as deciding about what to eat and drink, how to spend their leisure time, when to go to bed, how to spend their money and so forth; to the extent possible, without exposing the individual to unreasonable risk.

- **Right to be visited and to visit others.** There must be a compelling reason to limit these rights (such as safety of the individual and/or others); and such limit would require the individual's or guardian's consent, as well as a

review by the provider's Human Rights Committee and the ISP team.

- **Right to reasonable expectation of privacy**; such expectation includes assistance, whenever possible by same gender staff for personal hygiene and related needs.

- **Right to engage** in **activities that promote each individual's meaningful community integration**. This includes any person needing staff support in the community. Program staffing levels should be sufficient to honor this right.

If your family member is not receiving the care they deserve, described in the Rights and DDS regulations above and agreed to in the ISP, you may need to help him/her speak up or speak up for them. To do so,
You can:

- **Contact** your Provider Agency's management staff &/or file a grievance with their Human Rights Committee

- **Contact** DDS Area Office staff, including the Service Coordinator &/or Area Office management.

- **Contact** your Regional DDS Human Rights Specialist or the DDS Director of Human Rights

- **File your complaint** with the DPPC (Disabled Person's Protection Commission) or with the DDS Regional Senior Investigator, if you suspect abuse, mistreatment or 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 DPPC's mission is**: "To protect adults with disabilities from the abusive acts or omissions of their caregivers through investigation oversight, public awareness and prevention".

- **The standard for reporting** suspected abuse and neglect to the DPPC is **"reasonable cause to believe,"** which means that mandated reporters (legally responsible) need only "**suspect**" that abuse or neglect was committed against a person with a disability to report this incident.
  Mandated reporters must report suspected abuse and neglect; and, if they fail to do so, they are subject to a legal penalty. Most persons employed to work with individuals with disabilities are mandated reporters.
  Non-mandated reporters include individuals, family members, friends etc. who believe an abuse or neglect has been committed against an individual with disabilities, are also encouraged to report suspected abuse and neglect.

  You, your family and friends or anyone may call the DPPC hotline or file their complaint by filling out a DPPC abuse and neglect complaint form (located at www.mass.gov/dppc).

What happens next?

Once the DPPC receives the call or report, they decide if the information given meets their legal criteria to either screen the case "IN" or "OUT." To screen it IN, the information provided must suggest **"an act or omission of a caretaker resulting in serious physical or emotional injury, including consensual sexual activity" has occurred.**

- **The State Police review each case** to see if the allegation may be considered criminal conduct; if so, they refer it to the local District Attorney for review and possible criminal investigation.
- **When a case is "Screened IN"** & State Police have referred it criminally, on, DPPC staff may conduct an investigation under DPPC's statutory jurisdiction; or the DPPC may assign the case to DDS' Investigation Unit, where DDS investigators will pursue an investigation, but use the DPPC investigation standard. The DPPC standard is "*the suspected abuse must involve a person with a disability who has sustained a* ***serious physical injury*** *and/or* ***serious emotional injury*** *as the result of an* ***act****or* ***omission*** *by their* ***caretaker****(s)"*
- **If a case is "Screened OUT**", it indicates the DPPC has determined that the information given does not meet DPPC's statutory jurisdiction for a DPPC investigation.
- If **"Screened OUT",** the DPPC will forward the case to DDS' Investigations Unit, which has different criteria for their investigations. The DDS standard for investigation is: "*Any complaint outside the jurisdiction of the DPPC alleging abuse, abuse per se, assault, sexual abuse, or financial exploitation of an individual*". This standard does not require that there was serious physical or emotional injury.
- **If the case meets this criterion,** the DDS Investigations Unit will conduct their own investigation.
- If the allegation does not meet the standard for investigation but still might be considered Mistreatment per 115 CMR 5.05 then the Investigations Unit will refer the case to the Regional Office for a **DDS Administrative Review.**
- If the allegation does not meet the standard for an investigation or an administration review the case may be referred directly to the Complaint Resolution Team for review and identification of any needed remedial services.

Following notice that an allegation has been received, the Provider Agency ***may need to take immediate action*** to protect the health and well-being of the alleged victim, while waiting for the outcome of either the investigation or administrative review.

https://malegislature.gov/Laws/GeneralLaws/PartI/TitleII/Chapter19C This link to Mass General Law chapter 19c, provides the legislative basis for the D.P.P.C. Section 4b, stating that the DPPC may refer cases to the DDS for investigation.

The Outcome of an Investigation or Administrative Review:

- **A copy of a Decision Letter regarding the investigation's outcome** will be sent to Individuals and/or their Guardians, along with the instructions for appealing that outcome of an investigation, or requesting reconsideration in the case of an administrative review.
- **The provider agency's human rights committee also receives a copy of the Decision Letter**.

What if you have called in a complaint to the DPPC and have not heard back from them or from DDS?

- **Call them**. If the case has been referred to DDS investigations unit or another body, call them. An investigation may take some time to complete, and they may not call you with updates. You can make the call to find out the status of the investigation so that you know your concerns are being followed up on.

DPPC is called 800-426-9009

DPPC determines if it protective action is needed.

If yes

DPPC works with DDS and others to insure immediate safety of the person

DPPC determines if the case falls within their jurisdiction

If yes

DPPC conducts investigation

DPPC may ask DDS to conduct the investigation under the DPPC 19c regulations

Disposition of case is reached, decision letter is issued

Individual, guardian, or human rights committee can file an appeal of decision

If no

DPPC refers the case to DDS investigations unit

DDS investigations unit determines if the case meets their criteria for investigation

If yes

DDS conducts investigation under their regulations

Findings are made, decision letter is issued

Action Plan is issued. Individual or guardian, and the Alleged Abuser may be able to file an appeal of the Findings or Action Plan.

If no

Case is referred for DDS administrative review

Administrative Review is conducted

Administrative review is completed

Or

Case is referred back to investigations unit

Complaint resolution team reviews matter.

Resolution letter is issued

Individual or guardian can file a request for reconsideration with the Regional Director

Call is screened by State Police to see if a crime may have been committed

If yes

Case is referred to law enforcement

Criminal investigation is completed before DPPC or DDS investigate

Resource List

- **Department of Developmental Services Office for Human Rights**
  Richard Santucci, Director 617-624-7738
  Rich.santucci@state.ma.us

- **Department of Developmental Services Website**
  http://www.mass.gov/eohhs/gov/departments/dds/

- **DDS regulations and policies**
  http://www.mass.gov/eohhs/gov/laws-regs/dds/

- **Disabled Persons Protection Commission**
  http://www.mass.gov/dppc/
  300 Granite Street Suite 404
  Braintree, MA 02184
  Phone: 617-727-6465

- **Disability Law Center**
  http://www.dlc-ma.org/
  11 Beacon Street, Suite 925
  Boston, Massachusetts, 02108
  Phone: (617) 723-8455 / (800)

- **Massachusetts Families Organizing for Change**
  http://www.mfofc.org/
  Massachusetts Families Organizing For Change
  PO Box 61
  Raynham, MA 02768
  Phone: 508-824-6946

- **The ARC of Massachusetts**
  http://thearcofmass.org/
  PO Box 541603 Waltham, MA 02454
  Phone: (781) 891-6270

- **Massachusetts Advocates Standing Strong**
  http://ma-advocates.org/

  https://www.facebook.com/Massachusetts-Advocates-Standing-Strong-231842356173/

- **Massachusetts General Law chapter 19C - DPPC**
  https://malegislature.gov/Laws/GeneralLaws/PartI/TitleII/Chapter19C

- **Disability info.org**
  https://www.disabilityinfo.org/