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# Rights Review

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Promoting Human Rights by providing information and discussion across DMR/DDS

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

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## Human Rights Forums!!!

This is the 25<sup>th</sup> anniversary of the annual DMR/DDS Human Rights Conference and it was at the first such conference that establishment of the Office for Human Rights was announced. While economics require us to re-focus our approach to the conference, this year we will celebrate 25 years of human rights safeguards with five free regional forum events!



**“Dare to Dream” John Anton giving the keynote speech at the 2006 Human Rights Conference**

The Department also is celebrating the success of so many self-advocates and other advocates, in their fight to see the name of the Department changed. As of June 30, 2009 the Department will

become the Department of Developmental Services.

We will take the occasion of the regional forums to take stock in how the political successes of the self-advocacy movement have mirrored success in the lives of all individuals in their ability to exercise real control in the main parts of their daily lives, choice of work types and jobs, and choice of where to live and type of living environments, for instance. We will explore the goals of the human rights system and how it works for providers and individuals.

At each forum we will celebrate our victories, recognize some of the people who have made a difference in promoting human rights and reflect on our history. We then will explore the existing human rights system, and how it works for providers. We will have a response from individuals supported by the

system. This will set up the agenda for a human rights town meeting with Commissioner Howe. We hope not to just lay out the current challenges, but to help forge some solutions, together. Please refer to the Department’s home page on the web for details on *how to register* for and get to the forums. The days all start at 9 AM and go to Noon. The dates and locations are as follows:

- June 3, 2009 at Holyoke Community College
- June 15, 2009 at the National Guard Museum in Worcester
- June 24, 2009 at Roxbury Community College
- June 26, 2009 at Massasoit Community College in Brockton
- June 29, 2009 at Middlesex Community College in Bedford (this is a change from the original notice)

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## ***Emergency Restraint v. Hold as Behavioral Intervention Redux***

**By: Tom Anzer**  
**DMR Director for Human Rights**

There continues to be some confusion about the difference between emergency restraints and holding used as duly authorized behavioral interventions in Level II Behavior Modification Plans. The question raised is when is holding written in a plan an Intervention for treatment purposes under 115 CMR 5.14. When it is, the agency is not required to report the holding as a restraint. If the clinician puts an emergency provision inside the behavior plan solely to keep the individual safe through use of restraint, people get confused as to how or if this should be reported as a restraint in HCSIS. The Department's Human Rights Advisory Committee recently recommended the Commissioner adopt the following approach, and she has agreed to this in principle. Clinical guidance will be forthcoming once crafted. She further intends to look at the behavioral regulations to update and revise them as a whole. The recommendations are as follows:

1. If holding is in the plan the clinician must declare the intent behind its inclusion; to provide for safety in an emergency or for treatment purposes, i.e. to physically support an individual in a manner intended to reduce the target behavior.
2. That if a hold is for safety only, clinical guidance regarding individual needs during an emergency should be written as an emergency protocol to be attached to the plan to avoid confusion.
3. It is sound clinical practice to anticipate times when a planned intervention may not

succeed and give guidance through an emergency protocol about the physical and psychological needs of an individual in an emergency.

4. To add a protocol for emergency intervention to a behavior modification plan does not constitute establishing a treatment purpose to the holding.
5. When adding such a protocol to a plan, instructions should be given to require staff to fill out emergency restraint forms in these circumstances.

If holding is truly a behavioral intervention in the plan, it has a well-articulated treatment role in decelerating the target behavior it is intended to address. Behavioral data will be captured to measure the effectiveness of the holding. The team needs to continually reassess to determine if it is fulfilling its treatment role.

An example of how holding can be used in a treatment intervention involves holding early in the cycle of escalation of a behavioral event, before an emergency exists, to interrupt a path to dangerous outbursts with an eye to keeping an emergency event from happening and help teach the person how to gain control for their selves. A technical definition can also include any intervention where the treatment procedure must be physically enforced to overcome the individual's active resistance, such as an escort to time out.

One myth in the system is that if a person has too many restraints it establishes a pattern that is "planned and predictable" and can no longer be defined as emergency events. This is false. If there is a certain frequency of emergency restraints (more than two in a week or three in a month) the team must assess the situation and identify teaching or other strategies or interventions that will reduce the need for emergency restraint. In other words, they have an

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obligation to figure out what is going on and intervene.

Another myth is that the Department punishes programs that have "too many" Level II plans. The Department is invested in the progress of all persons in maximizing their ability to fully integrate into typical life activities and settings. While programs trying to help persons change behavior that limits their community participation have an obligation to try less restrictive interventions first, if an agency has Level II plans and can demonstrate less restrictive interventions tried, and the behavioral data shows the Level II plans are working, these agencies will be applauded, not criticized.

If holding is found by the Peer Review Committee, the Human Rights Committee and the team, as a legitimate intervention with a clear treatment role articulated in a behavior modification plan, the holding is not required to be reported as an emergency restraint.



### **Exercising Human Rights**

**By: Rich Santucci, HRAC**  
(Rich recently completed his term on HRAC but graciously agreed to let this article he wrote during his term be published)

Though constitutional, legal and civil rights are intended to protect all members of society, including those we support, DMR Regulations

[including 115 CMR 3.09 and 5.01-5.16] provide many additional protections for individuals to reflect Federal Court decisions which have addressed historical violations of the constitutional rights of individuals with developmental and other disabilities.

One of these important additional protections we provide for the individuals we support is to assure their knowledge of their rights through individualized teaching and opportunity to exercise them. We are mandated to do.

### WHAT IS REQUIRED?

I. According to 115CMR 3.09

(b): The general responsibility of the [human rights] committee shall (include) “ 4. to monitor and review the means utilized by the provider or agency to:

- a. **inform individuals, staff, guardians, and families of the individual's rights;**
- b. **train individuals served in the exercise of their rights;**
- c. **provide individuals with the opportunities to exercise their rights to the fullest extent of their capabilities and interests;**

So, the human rights committee of each provider agency is responsible to insure that the agency is providing the human rights training.

II. The regulations (115 CMR 3.09) go on to specify who actually provides the training:

(3) The head of every provider shall designate and empower a person employed or affiliated with the provider or agency to serve as the provider's or **agency's human rights officer** and to undertake the following responsibilities as a formal component of his or her job description for the provider or agency:

- (b) **1. to inform . . . individuals served, . . . of the**

**individuals' rights, including making copies of 115 CMR 5.00 available for inspection at any time by each individual;**

**2. to annually train individuals served in the exercise of their human rights, to the maximum of their capabilities and interests (with such annual training to be documented in the individual's record), and to assist them to exercise those rights;**

**3. to provide individuals served with opportunities to exercise their rights to the fullest extent of their capabilities and interests, including informing them of the grievance procedures and the right to go to the human rights committee on any issue involving human rights;**

The regulations thus require:

- (1) documented annual training which addresses both the individual's learning capacity and personal interests; and
- (2) the ongoing requirement to assist in the exercising of rights.

### HOW IS THIS ACHIEVED?

A major challenge in achieving this mandate is addressing the incredible diversity of individual learning styles and capacities of folks. Annual training should include how to exercise rights as well as list them in a way similar to Miranda rights ('you have the right to receive mail, you have the right to make and receive phone calls, etc., etc...') The training curriculum will have to account for the cognitive capacity and learning style of each individual. This suggests having access to a variety of materials and approaches which may be adapted for particular individuals. One size never fits all when it comes to human rights training.

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An additional consideration for individualized human rights training is to maximize choice by considering how the person might best be able to exercise rights in a way that is personally meaningful. The lifestyle, preferences, support needs, and type of services that the person is receiving will have a lot of relevance in determining in what areas to focus. For example, choosing where one wants to live may be crucial for one individual, while for another it may be more relevant to participate more fully in health care decisions.

If we can provide training on exercising human rights that is appropriate to the individuals' learning style, capacity, and ISP objectives, and if we can focus on areas of the individuals' lives which are important to them and plan for success, we will succeed in making teaching human rights a part of every day life. In this way, it will not be an extra duty for staff to perform. It will not be a once a year, once a month or even once a week exercise for individuals. Teaching human rights will become a perspective which is applied to activities and decisions of everyday life, be they big or small. What we are having for dinner tonight, what doctor do I want to see, where do I want to work, what channel do I want to watch on the TV, why does city trash collection pose a problem interfering with my household maintenance and to whom do I complain, etc. . . . By utilizing an individualized approach to teaching about human rights we may also be able to make the learning process a regular part of daily life.

One additional resource for Human Rights Officers identified in the regulation notes that training and opportunity requirements are to be provided “with technical assistance of the Department” [115 CMR 3.09 (3)(b)]. What technical assistance can the DMR provide for those Human Rights Officers who must foster learning in such an all-encompassing, global manner?

Three main areas of support are:

1. Helping identify appropriate training materials,
2. Participating in HRO training of the Department
3. Providing suggestions and detailed consultation for specific homes or individuals on a case by case basis through the regional human rights specialist.

### WHAT DO I DO NOW??

How can you as the Human Rights Officer approach the complex yet important endeavor of supporting individuals in exercising their human rights? Many “tried and true” approaches and suggestions are already well-known and utilized across the state, and are listed below. Providing rights training and opportunities can be approached from three perspectives: (1) individual, (2) group, and (3) organizational/community.

#### I. INDIVIDUAL

- Assess the learning style, training needs, and preferences of the individuals who you serve. You can develop your own assessment tool or utilize and customize one that has already been developed
- Develop a teaching plan for each individual
- Work with the individual to identify a goal that is meaningful to them for exercising human rights.
- Personal human rights scrapbooks which could have pictures of each individual exercising their rights in a way that is meaningful to them.
- Try to engage the individual in developing a human rights goal to work on during the year. If this can be incorporated into the ISP, then you can be doing two things at once;

helping to teach the exercise of human rights, and working on the ISP. Even the act of including the exercising of one’s human rights as a goal in the ISP with the input of the individual, is in itself an achievement of exercising rights.

- Utilize teachable moments to problem solve with a human rights perspective.
- If an individual is displeased with some agency procedures that they feel are restrictive such as a behavior plan which has been consented to by a guardian, you can help them to receive and explanation of the need for the plan and the criteria under which the need for the plan is being based, what they would need to demonstrate or achieve to have the plan modified or eliminated, and the process by which the ongoing need for the plan is evaluated.

#### II. GROUP

- Make sure that the exercising of human rights is one of the regular topics at house, worker, or other ‘consumer’ meetings.
- Promote discussion of human rights in group problem-solving, especially where conflict resolution is necessary, or where group decisions or taking turns is required.
- Provide environmental/informational resources in daily life on bulletin boards, newsletters, event planning, etc.

#### III. ORGANIZATIONAL/COMMUNITY

- Locate and access people who can make presentations,

- Visit, access, and become familiar with places where rights can be accessed, demonstrated and exercised (city hall, other local state and federal government resources)
- Identify all of the teaching resources that are available, both ‘canned’ from training organizations, and ‘homemade’ within your own agency. This can include DVD’s videos, written material, picture books. It can also include ideas’ such as individualized human rights booklets, and materials you and your fellow agency staff and individuals develop.
- Utilize a process for evaluating the progress that each individual is making in exercising their human rights.
- Make sure that the exercising of human rights is one of the regular topics at team meetings or staff meetings.
- Convene with your fellow human rights officers to share ideas, challenges and successes
- Communicate with the Human rights committee on your progress
- Work with a local college or community access television to make your own human rights movie
- Promote membership in a self advocacy group such as Mass Advocates Standing Strong. If there is not local chapter in your area, consider starting one
- Promote civic participation by facilitating access to municipal government committees, city council meetings, meetings with elected officials, etc.



## Update on Human Rights and Regulatory Issues:

1. Programs providing training on emergency restraints and physical holding in plans have been implementing approved curricula. Since this initiative ensured de-escalation tactics are taught to all staff trained on restraints, there has been a more than 24% drop in the number of restraints applied statewide between FY '07 and FY '08! The Department's initiative to coordinate clinical teams in each area may have also played a role in this reduction. The last of the training programs to be reviewed has recently been approved so all provider agencies should be using approved training programs by now. Documentation related to this training will be expected to come from the headquarters of the training program.
2. The Department's Human Rights Specialists play a significant role in supporting the affirmation and protection of the rights of individuals. They continue to provide technical assistance, and training for provider and Department staff and Human Rights Committees, and share their expertise when asked for help. They can initiate or be asked to get involved in:
  - Complicated risk cases or situations that may require restrictions in the life of individuals by either area or provider staff, who may themselves be concerned they not be too quick to place restrictions on an individual.
  - Contact with the Area or provider staff to resolve restraint questions resulting from the Commissioner's review of restraints.

- Concerns about persons in their care with ten or more restraints per quarter.
- Finally, in their ombudsperson's role, an individual, guardian or family member with the approval of the individual may ask them to help them with certain issues that give them concern

Depending on the legal status the person who has initiated the contact, the Specialist may get involved in supporting resolution of their concerns. This may mean helping interpret the circumstances or helping them to clarify what is being communicated to them.

The ISP team remains the locus of discussion, the Specialist helps the individual obtain a satisfactory resolution, most often (depending on the issue) through the ISP process. The Specialist can be helpful, though, when either the message to the individual or guardian is unclear to them, or these parties feel unheard in the process. Usually, this involvement helps individuals and family members come to understand and be more comfortable with proposed plans.

From time to time when the Specialist comes into a complicated case at the request of an individual or guardian, staff at any level can react with surprise, sometimes even raising anxiety levels. *Everyone* in the system is working hard under difficult circumstances. It is understandable that this can raise concerns, but we must all understand that their involvement is at the request of the individual or their guardian, or sometimes even the provider. Everyone can benefit from this extra support, if it means there is a clearer consensus about the

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benefit of changes to support for an individual.

Specialists have also been brought into places where there are some differences among members of the team. They have been asked to attend ISP meetings, and other team meetings, to help individuals or guardians file complaints, to help individuals obtain counsel or to simply meet with a guardian and the clinician writing a behavior plan for their ward. All of these circumstances are necessary activities because a person who is subject to the proposed plans or actions, or their guardian has sought the help of the Specialist

They also play these roles both in the community and facility settings. In each facility, the Specialist is the Human Rights Coordinator, so they know many of the staff and others involved.

Human Rights Specialists get involved in hundreds of cases statewide every year. Often the caller wants simple one time explanations of the regulations and Departmental procedures, so they can better follow through on their own. Sometimes a much more involved participation is required. Either way, their role is to further the interests of the individual and further the resolution of situations that seem hard to close.

### HRAC Reaches Out

**Cynthia Piechota, Chair, Human Rights Advisory Committee**

All who directly or indirectly participate in the Department's community have a role to play in promoting and supporting human rights for people who are supported by the Department, including the people we support. The rules that are in place to govern this work can be very complicated and for many are very confusing. I am reaching out to

all of you in this article to get your involvement in a process that can help make these issues clear.

The Human Rights Advisory Committee has a number of roles, including advising the Commissioner on the promotion of human rights and assisting the Commissioner on the design of training programs for Human Rights Committees, Department and provider staff regarding the human and civil rights of the individuals we support. Several years ago we offered guidance to providers on minimum standards for Human Rights information to share with families, including specific documents and contact information relevant to the local program.

A major tool we have, though it has been a few years since we have used it, is this newsletter. *Rights Review* can serve several purposes. One, it can be a means to raise issues that appear outstanding or unresolved to local Human Rights Committees, or others. It also can provide guidance and technical reviews of hot issues or rights areas that are being re-thought.

We want you to tell us about your on-going concerns about different types of situations or your ideas for resolving some. While each issue is reviewed by Executive Staff of the Department to ensure that answers in this newsletter reflect the Department's policies, it can still be a forum for sharing back and forth. If you (anyone reading this is a member of our community) have an issue you would like an answer to, or would like to write an article that promotes unique solutions to difficult or common problems, please contact me by email (cynthiap@microtek-cables.com) and I will get back to you about your interest.

On the other hand, we need more direct involvement in our activities. HRAC is looking for a handful of people who have significant

experience in our system to become members of our committee. We are particularly weak in the Southeastern Region (though we have a new member from there) and the Metro Region of the statewide community. We are looking for more self-advocates and other persons from human rights committees on the provider level. We need more general advocates familiar with the Department and how it works. Please feel free to contact me or Tom Anzer and we will get back to you about your interest.

This year the Commissioner asked HRAC to look at the restraint regulations to see if there are recommendations we can make for updating them. Practice in the field regarding use of restraints have been improving (see above for decrease in frequency of restraints). We hope to make it easier to comply with the regulations while focusing them better on outcomes. We will also be looking at issues of safeguarding individual rights to privacy and sexuality.

Please feel free to contact me if you have an interest in volunteering, an issue you want addressed, or an article about your agency's best practices. We want to hear from your

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**Editor's note: Each issue of the "Rights Review" is reviewed by DMR senior staff and represents the views and regulatory interpretations of the Department as a whole.**

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### HRAC Members:

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 (provider's human rights coordinator)  
**Diane Iagulli**  
 (provider's President/CEO, and ADDP)  
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 (Governor's Commission on MR)  
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