

Human Rights Committee Webinar 2020

Responses To Webinar Questions

Where can we get training and resources to support HRC members?

[https://www.ddsn.sc.gov/sites/default/files/Documents/Consumer/HRCManual%20\(081018\).pdf](https://www.ddsn.sc.gov/sites/default/files/Documents/Consumer/HRCManual%20(081018).pdf)

How do you propose ensuring confidentiality (not discussing others) when there are persons who receive services also serving as a Member of the Committee?

The expectations for confidentiality are the same for everyone serving on the committee. All people should sign a HIPPA/confidentiality agreement as well as the support and training necessary to understand the expectations regarding confidentiality.

You mentioned that committees "approve" restrictions. Should it be the role of a Human Rights Committee to approve the restrictions or should it be to ensure that the persons rights are being protected if a right is going to be limited.

Human Rights Committees are to be established to protect all people's rights. Historically, there have been jurisdictions that require some other entity that would review clinical aspects of restrictions, support plans and medications. It is important to remember that the role of a Human Rights Committee is to uphold rights, and they may not have the capacity nor want the responsibility to perform clinical review. Based on the laws in your jurisdiction, it may be appropriate to have separate committees for each of these distinct functions.

How do you handle the situation where everyone who lives in the home has a restriction (i.e. locked fridge due to someone with prader-willie) and the team deems it as a non-issue? Should these still be taken through and how should this be recorded?

In this scenario, each of the people living in the home should be afforded appropriate due process over all restrictions that affect them. In all scenarios, every restriction imposed upon people by organizations should receive due process, even if this restriction is in place to support someone else. Informed choice over all decisions is a fundamental component to exercising rights. Do people have a choice to live or work in an environment where they are not subject to restriction based upon the support needs of another person? The organization should consider ways to mitigate the effect that this restriction has on other people, such as providing each person their own individualized access to the restricted item without having to ask staff for permission or access.



Describe how a Support Coordination organization that is not funded through HCBS would establish their own committee, i.e. what is this entities role? Restrictions are applied while person is receiving services from direct support providers, not the Support Coordination agency, so it's unclear of the entity's authority.

The role of a Human Rights Committee at a Case Management/Support Coordination provider may be different than that of a committee operated by providers of direct support. First and foremost, the committee's primary role is to uphold the rights of all people receiving services. The committee Case Management/Support Coordination provider might still have the responsibility to review support plans to ensure they have had appropriate due process at the organization of origin with the person present. Additional roles might include review of policy, ensuring that no blanket rights restrictions, review and mediate grievances, and support education throughout the organization as it relates to rights issues.

Should the HRC meetings always be held in person? Or could they be held over a telephone conference or Skype?

As with any meeting, there is value in face-to-face, in-person interaction. However, organizations have been successful in offering access via skype or telephone for people to attend Human Rights Committee meetings where they otherwise would have been unable to attend.

Is it a rule that a person cannot sit on the HRC committee at an agency if they are employed by another similar agency?

CQL | The Council and Quality and Leadership does not have a rule or any formal recommendation that members of Human Rights Committee members not be employed by another service provider. We do suggest that you review the appropriate regulations and guidance in your jurisdiction to ensure that this is not a requirement where you provide services. We do suggest that you recruit a diverse membership, and include members that do not work in this field in order to foster a variety of perspectives within your committee.

What are your recommendations regarding safely and responsibly fading out interventions which have enabled an individual to be successful at day program (or any setting) and also ensuring the safety and rights of others?

We encourage you to regularly assess alternatives to restrictive approaches, and the possibility of fading restrictions whenever possible. However, we don't suggest you do this in a way that would present a risk to other people using or living in the same environment. Behavior = Communication. What is the person that is being restricted trying to communicate to you? Have they made an informed choice in regards to day programming, work, or where they live? Would they prefer to do something else or live somewhere else?

Can you give examples of what a privilege is vs a right?

Privilege as a concept is more abstract than rights. People who have a great deal of personal wealth are “privileged” in that they can afford certain luxuries. The family of a teenager may give them the “privilege” to use the car. Privileges are frequently “allowed” to people who may have limited rights, such as people who are incarcerated. It is important to remember that people we support have the same rights as all other people, and we should not consider any right that any other person would have to be a privilege. In our society, rights cannot be limited or taken away from people without proper due process, such as a court proceeding. In organizations, rights are sometime limited through due process via a Human Rights Committee proceeding. The UN Declaration on Rights is a good guide to understanding fundamental rights.

We would appreciate suggestions on increasing active participation of people receiving services on the committee.

It is important that all people have the support needed to be an effective, contributing member, and feel that their perspective is valued. We have seen organizations effectively support people through pre- and post-meeting conversations and other forms of support. Generally, what works for all members will work for people being supported. Is the meeting at a time that is convenient? Do I have a reliable way to get to the meeting?

What are your recommendations regarding safely and responsibly fading out interventions which have enabled an individual to be successful at day program and also ensured the safety and rights of other individuals? My agency supports an individual who has demonstrated behavior of a sexual nature across a variety of settings which, had he not been identified as a person with a developmental disability, would have resulted in legal entanglements and possibly incarceration. At day program, he is accompanied throughout the building by a staff member. He likes the company and has no problem with it but also understands the "why" as to why this occurs. This intervention has allowed the person to remain at day program and to succeed. It also ensures that others remain safe. The data over several consecutive review periods would indicate that no sexual impropriety has occurred, but it is precisely BECAUSE of the protections we have put in place.

Based on what you have described, it sounds like the restriction in place is necessary and working effectively. Again, we do not suggest that you remove restrictions in a way that would put others at risk. There are some additional elements to consider: It is important that the person is making an informed choice- Is the person aware of the alternatives to this type of restriction? Does the person have the option to do something else during the day such as work? We would recommend that all restrictions receive periodic review regardless of how effectively they are working, as people’s perspectives and support needs change over time. No restriction should be a life sentence regardless of how well it is working or how badly it is needed.

Following up on the earlier slide regarding the federal HCBS Settings Final Rule: in Colorado, we have determined that the rule doesn't alter the scope of what goes before the HRC. If a matter historically went before the HRC, it still should. If it didn't, it still shouldn't. Are other states taking a different approach?

States have varying frameworks and regulation around Human Rights Committees. Some states do not have any regulation around Human Rights Committees at all. The states are at varying stages of having their HCBS transition plans approved by the federal government. In general, what was a restriction before remains a restriction under the new rules, but providers should have a heightened awareness of practices that may be considered restrictive under the new rules. In addition, there is increased emphasis on documentation, so we continue to recommend that Human Rights Committees maintain comprehensive meeting minutes in order to document that restrictions have been reviewed, and that the person-centered plan document the rationale for any restriction imposed, and what the plan is for fading the restriction over time.

Regarding people with legal guardians, should we discuss informed consent with the adjudicated person, as well as legal guardian?

Yes. The person's perspective is important, and they should be involved in the process at all times even if there is a guardian or some other type of decision-making authority in place.

Regarding Confidentiality, do you recommend that when committees are reviewing a limitation of a person's rights that all identifying information about the person be removed from any documentation that is given to the committee? (If the individual attends the review then this would not be applicable)

In practice, this may be difficult to achieve given that people should be supported to attend the HRC meeting when their restrictions are being reviewed. Having a person connected to the plan may be difficult to avoid. Rather than redacting, it may be better to have all committee members sign HIPPA/Confidentiality agreements and have support to understand what the expectations are in this area.

After explaining the concerns to the person who may have a right restricted, what happens if the person does not agree to it?

The function of "due process" is to ensure that restrictions are being implemented fairly. Legal systems provide due process for people accused of crimes, just as human rights committees provide due process for people being restricted in some way by an organization. Restrictions often serve a function, such as ensuring health or safety. People should be supported to make an informed choice in regard to restrictions that are being put into place. Informed choice includes understanding the consequences of choosing not to have a particular restriction in place, which may include an organization no longer being able to support a person if the risk without a certain restriction in place would be significant enough that it could put the person and/or others in danger. Informed choice should also include the opportunity to receive services in another location or from a different provider.

We support people who are their own guardians and who choose to still have restrictions. They have at other points been on formal and informal programming to lessen restrictions, but they still choose to keep that restriction (e.g. not independent in medication administration). How would you recommend proceeding? Would this be rationale enough to keep a restriction?

As providers, we should understand that because of our traditional tendency to over-support and do things for people, a level of learned dependency continues to exist. Does your organization truly have the staff resources to over-support people? Is it fair to others that limited staff resources are being directed towards a person who really does not need them? Depending on the situation, staff supporting a person to take their medications may be considered a support rather than a restriction, but the person should be supported to understand that it is their responsibility to work towards administering their own medications. Respect is often defined by our actions, and in this case, we can respect this person by challenging them to learn how to manage their own health care. We challenge all organizations to move away from a culture of care to a culture of support.

I know this webinar is about rights committees and not rights, in general but would you please speak to the issue of video camera monitoring in environments used by persons who receive services and supports? Often the cameras are reportedly to monitor the staff activities in those environments and to help keep people safe. What is best practice in such cases?

Most restrictions are put into place to support people to be safe or healthy. Even when a restriction is being implemented to provide for a person's health or safety, they should still receive appropriate due process and have a plan to fade the restriction over time. Video monitoring is a restriction as it infringes upon a person's privacy and as such, should receive appropriate due process.

What percentage of the HRC should be non-employees?

Ideally, all voting members of the HRC should be unaffiliated with the organization. Minimally, restrictions should only be approved via a vote of two-thirds unaffiliated members.

Restitutions should be time specific. If the clinician states that the restitution will be reviewed in 6 months or 12 months, is that time specific?

Yes, although for some restitutions or restrictions, it may be more appropriate to review progress sooner than 6 or 12 months.

If you have a state run HRC should agencies pursue their own internal one as well?

Depending on the function and make-up of the state-level committee, there may be times when organizations will want to provide additional or supplemental due process. The organization should consider: How is the person being represented at that meeting? Are they present with an advocate for their wants and desires? What is the make-up of that committee? Does the state-level committee review organizational policy and uphold rights at the organization? Does the state HRC share minutes/other documentation from this meeting with the organization?

What if the person refuses to consent to the restriction?

The HRC provides due process and assesses the fairness of the restriction, and if approved, the restriction can be implemented. However, the person must be given all of the information necessary to make an informed choice about this restriction, including the opportunity to choose another provider.

If an individual needed a fork or spoon and support staff forgot to provide it, how is that a rights restriction? I could see it as one if the staff refused to provide, but just to forget?

Failure to provide a needed item to a person would not be a rights restriction but should be reviewed as an incident as it might meet the criteria for neglect.

Can we have some of the same members on the HRC and BPRC?

While in most circumstances CQL may not consider this a conflict, we encourage you to review the laws and regulations in your jurisdiction. Again, we encourage you to support a diverse membership and a variety of different perspectives on your Human Rights Committee.

I didn't register ahead of time. How do I get the follow-up email?

If you do not receive the follow-up email, please visit our website for a video of the webinar and download of the materials. <https://www.c-q-l.org/resources/webinars/>. If you need proof that you have attended, please email training@thecouncil.org.

Do you know of any picture rights resources/packets for individuals to help them learn some of their rights?

CQL publishes Rights Conversation Cards provide a fun and engaging way to spark discussion about a variety of rights involving decision-making, due process, privacy, voting, healthcare, finances, accessibility, and more. They are available at <https://www.c-q-l.org/resources/rights-conversation-cards/>. There are a number of resources online and providers willing to share resources that they have developed. Please visit the [CQL E-Community](#) on Facebook.

What are your views on Regulations that indicate a person with a specific diagnosis (i.e. intermittent explosive disorder) is REQUIRED to have a behavior support plan? (i.e. their behavior may not indicate a need and the fading component is almost obsolete)

We encourage you to comply with the laws and regulations of your jurisdiction. Not all support plans include restrictive interventions, so it is possible to use your plan to promote proactive strategies to support the person.

On Guardianship, what if person doesn't agree with the Guardian?

The organization's primary responsibility is to the person receiving supports. We encourage you to advocate for the person but understand that sometimes we must achieve balance and we are bound by law to respect the wishes of guardians. Because guardianship limits the decision-making authority of the person, it should be viewed as a restriction and be given ongoing due process. Organizations can support people and their families to explore other less-restrictive options such as supported decision making, power of attorney, or the person becoming their own guardian.

Does an Incident Review Committee take the place of HRC in reviewing abuse, neglect, etc.?

No. The HRC and Incident Review committees play separate and distinct roles within the organization.