



# Oregon

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Department of Human Services  
Office of Developmental Disabilities Services (ODDS)  
Senate Bill 834 Legislative Report  
2017 Regular Session

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In accordance with Senate Bill 834, enacted June 14, 2017, the Department of Human Services respectfully submits the following proposal, which contains recommendations for the establishment of an independent human rights commission to safeguard the dignity and basic human rights of individuals with intellectual and developmental disabilities. These recommendations represent consultation with stakeholders in the intellectual and/or developmental disabilities community, including the state protection and advocacy system, the Oregon Council on Developmental Disabilities, and the Oregon Self-Advocacy Coalition.

A workgroup was convened to collaborate on recommendations for a human rights commission. The workgroup met four times and included the participation of self-advocates, family members, providers, and the Department.

This report is formatted to align with the layout of Senate Bill 834. Listed below the bill language is the summary of specific recommendations, followed by documentation of the work group discussion related to the recommendation.

**SECTION 1. (1) The Department of Human Services shall develop a proposal for the establishment of an independent human rights commission to safeguard the dignity and basic human rights of individuals with intellectual or developmental disabilities, including but not limited to the right of individuals to:**

- (a) Choose their friends and visitors;**
- (b) Select their own entertainment;**
- (c) Tend to their own personal hygiene;**
- (d) Choose their intimate partners; and**
- (e) Have access to food when they choose to eat.**

Recommendation:

The workgroup proposes the human rights commission review and provide advice to ODDS, local providers, individuals, families, and other concerned parties, for situations brought forth to the commission when:

- Individual service plans include restrictive interventions as a means of providing support;
- There is disagreement between the individual and their guardian or team in relation to the exercise of personal freedom;
- There is disagreement between the individual and their guardian or team in relation to approval of restrictive interventions;
- There is a need for identification of the level of individual understanding in regards to the risks associated with a choice, strategies to mitigate associated risk, and the role of the provider associated with individual risk taking; and/or
- It is believed that the individual's identified plan or supports included in the plan are the result of undue influence by other parties, including situations where psychotropic medications are administered to individuals without a co-morbid mental health diagnosis

Discussion:

Individuals with intellectual and/or developmental disabilities, and society, benefit when individuals: exercise choice and self-determination; live and work in integrated community settings; and access supportive services based on individual choice regarding services, providers, goals and activities (ORS 427.007(1)(a)).

In line with these values, a human rights commission would:

- Safeguard and protect the rights of individuals receiving services to ensure that they are treated with dignity and respect in full recognition of:
  - their rights as citizens as opposed to their rights as consumers, and
  - their inherent right to fully benefit from the responsibilities and risks associated exercising these rights.
- Review and advise regarding issues which present ethical questions involving individuals who receive services from Oregon's Office of Developmental Disability Services (ODDS).

Oregonians receiving ODDS services shall be empowered and supported to bring issues impacting their human rights to this commission.

**(2) In the development of the proposal, the department shall consult with the state protection and advocacy system described in ORS 192.517, the Oregon Council on Developmental Disabilities and the Oregon Self Advocacy Coalition.**

**(3) The proposal must include:**

**(a) Any legislative changes needed to create and empower the commission;**

Recommendation:

The creation of an independent human rights commission in Oregon would require a legislative mandate for the creation of such a body as well as allocation of funding to support the entity.

The legislation would need to address the structure of the commission's operations, required composition, and mission. The scope of authority of the commission as an entity and its members would also need to be addressed in legislation. Additionally, the commission's operation and designees would need to be excepted from public meeting laws to protect the privacy of individuals going before the commission (ORS 192.690).

Discussion:

Members of the workgroup expressed that there are numerous existing workgroups, systems, processes, and stakeholder groups that have similar purposes and functions. It is recommended that Oregon's human rights commission function in a role that does not duplicate existing structures. Further analysis is needed to evaluate which duplications exist and how the commission might serve as an efficiency. The commission should operate to address those situations of safeguarding individual rights where there is not an existing process or protections in place. The scope and authority of the commission should be targeted, yet declared in a manner that is broad enough to allow for adaptation and evolution. The goal is the creation of an efficient entity that protects individual's rights, and compliments the existing service systems providing supports to individuals in Oregon.

**(b) The cost of administering the commission;**

Recommendation:

The establishment and operation of a human rights commission serving individuals with intellectual and developmental disabilities will likely have a fiscal impact. The workgroup recommends funds be used to establish a centralized commission with statewide authority and also regional commissions that receive support and direction

from the centralized commission. Additional funding adequate to support the structure of local committees and a central commission body should be allocated appropriately. Funding requirements include administrative expenses, as well as funding to engage experts such as national policy experts, specialists, clinicians, and practitioners.

Discussion:

Cost drivers include, but are not limited to, staffing (program administration, coordination of commission members, meetings, training, information, etc.), location costs to facilitate commission meetings, training for commission members, public outreach, travel costs for staff, commission members, individuals/advocates coming before the commission, supplies (including remote technology), consultation compensation, and recruitment.

**(c) A recommendation for whether the commission should be an independent entity or housed within another state agency;**

Recommendation:

The human rights commission should operate independently from the Office of Developmental Disabilities Services (ODDS) to the extent possible, with an option to be housed under the State of Oregon Department of Human Services. The commission structure and operations should include substantial operational safeguards to enable it to make independent recommendations. It is expected that ODDS leadership will participate actively in the commission, but do so without disproportionate authority in commission recommendations.

Discussion:

Safeguards include requirements for adequate representation of the disability community (including individuals, family members, advocates, and community partners), as well as equal standing of those representatives as members of the committee panels.

The workgroup was not able to arrive at a clear point of consensus on specifically where the commission should be housed. The workgroup concluded that the recommendation would be presented in such a way to allow for additional options for housing the commission to be explored.

**(d) How to guarantee the independence of the commission from influence by service providers and the department;**

Recommendation: With proper safeguards and processes in place, the integrity of the human rights commission and its ability to operate independently would not be compromised by being housed within a state agency such as the Department of Human Services. Safeguards include diversity of membership, clarity of scope of the commission, defined roles of membership, authority and funding to engage expert panelists, and a process for contesting decisions of local committees. All members of the commission should have the same standing to help protect independence. Legislation protecting the operation of the commission must articulate that all commission members have equitable standing and committees must include a minimum number of members, including:

- An individual service recipient, self-advocate, and/or OSAC;
- A family member of an individual receiving services;
- A representative from a disabilities advocacy entity, including DD Council;
- A representative of a provider group;
- Residential Facilities Ombudsman (or Long-Term Care Ombudsman or Oregon Health Authority Ombudsman, as appropriate);
- Disability Rights Oregon;
- Leadership from the Office of Developmental Disabilities Services
- A representative serving as an expert on Oregon-approved behavior intervention curriculum; and
- The addition of professionals as related the situation or issue, including national policy experts, medical professionals, practitioners, and clinicians. The experts could be maintained as a panel available for consultation as necessary.

Discussion:

The commission needs to have its specific role and authority clearly defined.

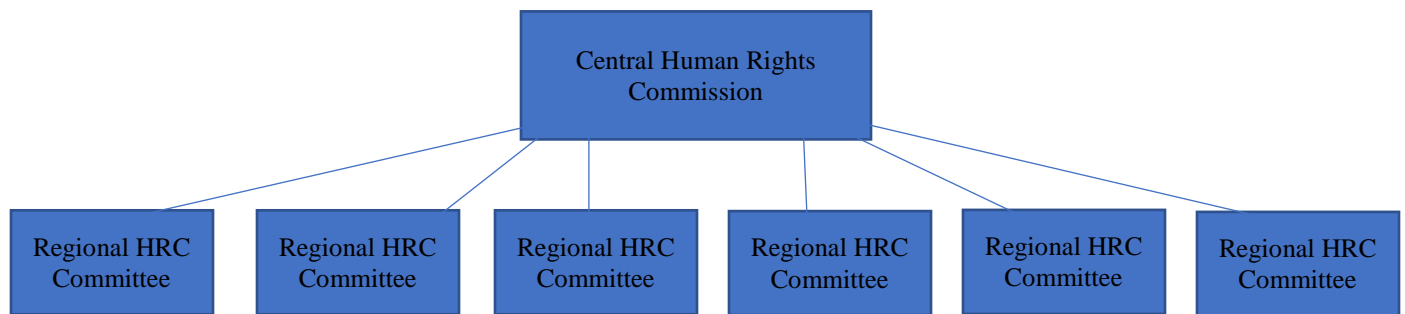
The workgroup identified the value of having regionally located committees drawing membership from local communities across Oregon. Regional committees could be operated under the guidance of a centralized body. Self-advocates in the workgroup expressed their belief that it would be easier to guide the work as advocates through a regional structure. The role of the local committees as part of a central operation

would also aid in mitigating the influence of ODDS and providers. The central commission body would serve to support consistency across regional groups, collect data on trends and best practices, etc.

The commission should have a clear process in place that allows for individuals to contest decisions of the regional committees and bring this forward to the central commission body.

Additionally, any person representing or having a paid or familial relationship with a specific provider, caregiver, or complainant shall not serve on the commission when there is any issue presented that involves that same individual. There should be a policy and procedure established to require members to declare their conflicts of interest with any specific item or person brought before the commission and a process for voluntary or requested recusal of that member for the duration of the item posing conflict.

It is recommended that the commission is empowered to engage experts for consultation on specific matters. Experts may include registered nurses or other healthcare professionals, behavior experts, mental health providers, education professionals, and others germane to the issues brought before the commission.



**(e) A comparison of similar commissions operating in other states; and**

This task was completed by workgroup- see attached appendix

Discussion:

Many states have adopted a human rights commission with a variation of form and functions. Composition of human rights commissions include commissions and committees operated under state developmental disability programs, as well as those operated as independent entities. Some commissions have a centralized structure,

while other states' models include local commissions operated within provider organizations, or by geographic region.

States also vary in the scope of responsibilities of their commissions. Some groups are tasked with evaluating and making recommendations for individual support plans, while others operate as an advisory entity on public policy and program operations.

All states share the common purpose of commitment to the preservation of rights of individuals with disabilities, and upholding their dignity.

**(f) An enumeration of the basic human rights to be safeguarded by the commission.**

Recommendation: While the committees shall hear from Oregonians receiving ODDS services on issues relating to their dignity, respect and rights as citizens, the committees can also consider hearing from Oregonians receiving ODDS services with concerns or limitations on their rights in the following issue areas:

1. People receive services in a setting that is integrated in and supports full access to the greater community;
2. Is selected by the individual from among setting options;
3. Ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint;
4. Optimizes autonomy and independence in making life choices; and
5. Facilitates choice regarding services and who provides them.
6. Individuals who access services in provider-owned or controlled home and community-based residential settings, they must also meet the following criteria:
  - a. The individual has a lease or other legally enforceable agreement providing similar protections;
  - b. The individual has privacy in their unit including lockable doors, choice of roommates and freedom to furnish or decorate the unit;
  - c. The individual controls his/her own schedule including access to food at any time;
  - d. The individual can have visitors at any time; and
  - e. The setting is physically accessible.

7. The individual's rights to lead and choose who participates in person-centered planning processes to determine their service plan.
8. Rights and values contained in ORS [427.007\(1\)](#)
9. Rights contained in ORS [427.107](#)



## Appendix: Table of States Comparisons

State	Purpose	Composition	Frequency	Other
Arizona	<ul style="list-style-type: none"> <li>Review any incidents that may have involved neglect, abuse or denial of rights;</li> <li>Review programs which might infringe on rights, i.e. programs using behavior modifying medications;</li> <li>Review proposed research involving people receiving supports;</li> <li>Make recommendations to the Division about changes needed to protect rights</li> </ul>	<p>Individuals and family members, professionals, advocates, and any other interested community members</p> <p>HRC members are recommended by local HRC committees and appointed by the Department director.</p>	1 x month	<p>Independent oversight</p> <p>Anyone can report or bring a situation or information forward to the HRC</p>
Colorado	<p>Reviews the use of:</p> <ul style="list-style-type: none"> <li>Psychotropic medications</li> <li>Restrictive procedures</li> <li>Suspension of rights</li> <li>Safety control procedures</li> <li>Emergency control procedures</li> </ul> <p>And reviews mistreatment, abuse, neglect, and exploitation investigations</p>	<p>Each Community Centered Board is required to have an HRC</p> <ul style="list-style-type: none"> <li>2 professional persons trained in application of behavior development techniques</li> <li>3 representatives of individual, parents, guardians, or authorized representative</li> <li>No employee of service agency within in the community centered board's service area shall serve as a member</li> <li>HRC limited to 9 members</li> <li>A quorum of 3 members must be present</li> </ul>	Meet no less than quarterly	<p>Serves as a third party mechanism to safeguard rights</p> <p>Use a standardized referral form</p>
Illinois	<p>Affirm, protect, and promote human and civil rights.</p> <ul style="list-style-type: none"> <li>Monitors and reviews activities of</li> </ul>	Each agency is tasked with creating their own HRC within the agency		Agencies determine the exact role of the HRC

	<p>the agency to assure that rights are upheld</p> <ul style="list-style-type: none"> <li>• Held accountable to question every situation where rights are restricted or denied</li> <li>• Reviewing means used to inform rights</li> <li>• Monitoring how rights are trained</li> <li>• Review policies and procedures annually to assure compliance</li> <li>• Assures legal counsel is available whenever a person faces due process</li> <li>• Monitors and reviews authorization and use of behavior interventions</li> <li>• Reviews and monitors the authorization of emergency rights restrictions</li> <li>• Makes recommendations on ways to improve promotion of rights</li> <li>• Assures that people with trauma are not retraumatized by behavior interventions</li> <li>• Reviews all rights complaints, all restrictive interventions (even emergency interventions), all use of psychotropic medications</li> <li>• HRC may review physical interventions and restrictions,</li> </ul>	<p>Membership includes</p> <ul style="list-style-type: none"> <li>• At least 5 members</li> <li>• At least 1 individual receiving services from the agency and/or the individual's family member</li> <li>• At least 1/3 member otherwise unassociated with the agency</li> <li>• No more than ½ of members employed by the agency</li> </ul>	<p>Each agency is required to establish a process for periodic review of behavior intervention and human rights issues</p> <p>Agencies have a choice in which model of HRC to adopt, including:</p> <ul style="list-style-type: none"> <li>• Stand alone (one agency)</li> <li>• Consortium (HRC shared by two or more agencies)</li> <li>• Combined Human Rights and Behavior Intervention Committees</li> </ul>
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	<p>medications, guardianship issues, incident reports, and money management issues</p>			
<p>South Carolina</p>	<ul style="list-style-type: none"> <li>• Safeguard and protect full rights as citizens</li> <li>• To review and advise regarding issues presenting ethical questions</li> <li>• Review, approve and monitor programs to manage inappropriate behavior</li> <li>• Review and approve plans which include restriction of personal freedoms, restrictive procedures, and medication as behavior management</li> <li>• Receive notification of use of emergency restraints</li> <li>• Review and advise on research proposals (rights focus)</li> <li>• Receive notification of abuse, neglect, or exploitation</li> <li>• Ensure prior informed consent is in place for any activity, plan or procedure that intrudes or has irreversible effects.</li> <li>• Review and advise on concerns that cannot be resolved through other efforts, including service plans, service and placement decisions, restriction</li> </ul>	<p>DD State Director appoints members to each regional HRC upon recommendation of the Facility Administrator and Associate State Director- Policy.  Current employees of DD Regional centers, local DSN Board, and contract providers may not serve on the HRC.</p> <ul style="list-style-type: none"> <li>• At least 5 members</li> <li>• At least 1 individual</li> <li>• At least 1 family member of an individual</li> <li>• A representative of the community at large with expertise or interest related to the I/DD field</li> <li>• A community professional with expertise in behavior or medical fields</li> <li>• Other community representatives</li> </ul> <p>Members serve a 3 year term (and may be reappointed for 1 additional consecutive term)</p>	<p>At least every other month- 6 times per year</p>	<p>HRC is an entity separate from the service organization</p> <p>HRC may consist of subcommittees, i.e. medication review, behavior support plan review, grievance appeal, ethics review, etc.</p>

	of freedoms, access to records, determination of ability to give informed consent, service termination, refusal of treatment services			
Tennessee	<p>HRCs serve as advisory committees to directors and ensure the human and civil rights of individuals are not violated. Specific functions include”</p> <ul style="list-style-type: none"> <li>• Review of behavior support plans that include restrictive interventions</li> <li>• Review any proposed or emergency right restrictions and restraints not contained in a BSP</li> <li>• Review of psychotropic medications</li> <li>• Review and make recommendations regarding complaints pertaining to human rights violations</li> <li>• Provide technical assistance to providers regarding policies and procedures affecting individual rights</li> <li>• Review and make recommendations regarding research to ensure projects will not result in rights violations</li> <li>• Ensure proposed restriction is the least restrictive option</li> <li>• Ensure that restriction is not for staff convenience</li> </ul>	<p>The provider executive director appoints HRC members at the local level  HRCs must have at a minimum 4 members, including:</p> <ul style="list-style-type: none"> <li>• A community representative who serves as chairperson</li> <li>• A minimum of 1 community representative from relevant professions with experience with human rights issues</li> <li>• A minimum of 1 family member of a person with a disability</li> <li>• A minimum of 1 person with a disability</li> </ul>		<p>Local HRCs may conduct business for a single provider or a group of providers. Providers are responsible for operational oversight and administrative support</p> <p>Regional HRCs may function like local HRCs but also resolve issues that cannot be resolved at the local level</p>

<p>Vermont</p>	<p>Independent Review of restraints proposed or occurring within supports</p> <ul style="list-style-type: none"> <li>• Review policies, procedures, trends and patterns</li> <li>• Individual situations and individual behavior plans including restraints</li> </ul> <p>HRC assists in developing positive alternatives to restraints</p>	<p>Individuals and family members, concerned citizens, and professionals.</p> <p>A majority of members must be present to review and advise on plans</p> <p>Membership is nominated and authority to appoint lies with the Department Director</p>	<p>Independent oversight</p> <p>Individuals, family members, guardians, DD staff and agency staff may submit information</p> <p>Any plan that includes restraints needs to be reviewed. Other support plans may also be submitted</p>
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