



May 1, 2020

Sent via electronic mail attachment

The Honorable Kate Brown
Office of the Governor
900 Court Street NE, Suite 254
Salem, OR 97301-4047

RE: Coronavirus and Health Care Rationing Concerns from Disability Advocates

Dear Governor Brown,

The Oregon Council on Developmental Disabilities (OCDD), Disability Rights Oregon (DRO), and the University Centers for Excellence in Developmental Disabilities (UCEDDs) at OHSU and the University of Oregon would like to acknowledge your leadership and dedication to protecting the health of all Oregonians during COVID-19 pandemic. Oregon’s commitment to non-discrimination and health equity are critical during these uncertain times. Thank you for your leadership and commitment to flattening the curve in Oregon. Your careful, yet collaborative approach to reopening our state has made Oregonians feel heard and supported, and we appreciate your coordination with our neighboring states.

We are reaching out to you as Oregon’s Developmental Disability Network or “DD Network”. Authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (the DD Act), University Centers for Excellence in Developmental Disabilities (UCEDDs), State Developmental Disabilities Councils (DD Councils), and State Protection and Advocacy Systems (P&As), operate in each state to protect civil rights and promote the health and wellbeing of people with developmental disabilities and their families through advocacy. As DD Network Partners, we work together to advocate for the principals of self-determination, informed individual choice, and the need to promote civil rights of people with disabilities. We believe the scarce resources and chaos of the COVID-19 crisis create conditions where people with intellectual and developmental disabilities are at risk for civil rights abuses, particularly in healthcare settings.

Historically, the rights of people with Intellectual and Developmental disabilities were violated through segregation, isolation, exclusion, and purposeful discrimination in the availability and delivery of health care and related supports. Unfortunately, this pervasive pattern of discrimination still exists today and extends to basic and specialty medical services, the wholesale denial of treatment from routine medical care to withholding life-saving

Institute on Development & Disability

Child Development and Rehabilitation Center

tel 503 494-2705
fax 503 494-6868

Rhonda Eppelsheimer, MSW,
LCSW Co-Director, OHSU UCEDD

eppelshe@ohsu.edu
www.ohsu.edu/ucedd

Mail code: CDRC
3181 S.W. Sam Jackson Park Rd.
Portland, OR 97239

medical treatments routinely available to other patients. These historical denials of fundamental rights occurred within a larger context that includes the eugenics movement in the United States.

As Oregon's DD Network, we align with the Office for Civil Rights at the U.S. Department of Health and Human Services (HHS), and would like to assist you to examine Oregon's emergency response plans and address any provisions that intentionally or unintentionally discriminate against people with disabilities. In particular, we want to ensure our states response aligns with this March 28, 2020 communication from the Office of Civil Rights.

The Office for Civil Rights enforces Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act which prohibit discrimination on the basis of disability in HHS funded health programs or activities. These laws, like other civil rights statutes OCR enforces, remain in effect. As such, persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.

Our organizations have already begun to hear concerns about bias and stereotypes from the disability community. Some of these concerns include inadequate supports for completing advanced directives paperwork and visitor policies that exclude key personnel for decision-making and communication support. The concept of providing services according to need is fundamental to health equity. Prioritizing the needs of people with disabilities in Oregon's response to the COVID-19 crisis is an important step in acknowledging the disproportionate affects the disability community experiences through intersections with higher rates of poverty, immunocompromised status, and increased risk of exposure to coronavirus.

Our network represents all Oregonians who experience developmental disabilities. We are here as a broad reaching resource for your office and ready to assist you to ensure Oregonians with disabilities concerns are addressed in this unprecedented time. Our network is here to serve the state and we respectfully ask you to:

- designate a representative from one of our organizations to serve on your office's Medical Advisory Group and the Disability Emergency Management Advisory Council to ensure the concerns of Oregonians with developmental disabilities are addressed now and in planning going forward
- designate a staff person in your office to receive complaints about healthcare rationing as it relates to people with disabilities
- in future communications from OHA, include a reminder to health care providers of their obligations under the law and require any training on

medical rationing makes clear that using disability as a basis to deny care is unlawful and unethical

- consider our respectful request to have a meeting with you or a senior policy representative from your office to better understand your plans to ensure the health and safety of people with disabilities and how we as the DD Network can contribute to and support future plans

Oregon must remain committed to ensuring an environment where people with disabilities have equitable access to health services and providers are free of discrimination. Oregon's DD Network organizations would like to help the state respond to this crisis in ways that are inclusive of people with developmental disabilities and their families. We share your vision for a recovery from this pandemic where Oregonians are safe, healthy, and productive. We appreciate your dedication to Oregonians during this difficult time, and we write today to offer our help.

Sincerely,

The Oregon DD Network Partners:



Rhonda Eppelsheimer, Executive Director
University Center for Excellence in Developmental Disabilities at OHSU



Beth Kessler, Interim Executive Director
Oregon Council on Developmental Disabilities



Jake Cornett, Executive Director
Disability Rights Oregon



Chris Murray, Executive Director
University Center for Excellence in Developmental Disabilities at the University of Oregon

HHS Office for Civil Rights in Action



March 28, 2020

BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)

In light of the Public Health Emergency concerning the coronavirus disease 2019 (COVID-19), the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) is providing this bulletin to ensure that entities covered by civil rights authorities keep in mind their obligations under laws and regulations that prohibit discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscience and religion in HHS-funded programs.¹

In this time of emergency, the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else.

The Office for Civil Rights enforces Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act which prohibit discrimination on the basis of disability in HHS funded health programs or activities. These laws, like other civil rights statutes OCR enforces, remain in effect. As such, persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities or age. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.

"HHS is committed to leaving no one behind during an emergency, and this guidance is designed to help health care providers meet that goal," said Roger Severino, OCR Director. "Persons with disabilities, with limited English skills, or needing religious accommodations should not be put at the end of the line for health services during emergencies. Our civil rights laws protect the equal dignity of every human life from ruthless utilitarianism," Severino added.

¹ Due to the public health emergency posed by COVID-19, OCR is exercising its enforcement discretion in connection with the conditions outlined herein. This guidance is a statement of agency policy not subject to the notice and comment requirements of the Administrative Procedure Act (APA). 5 U.S.C. § 553(b)(A). For the same reasons explained above, OCR additionally finds that, even if this guidance were subject to the public participation provisions of the APA, prior notice and comment for this guidance is impracticable, and there is good cause to issue this guidance without prior public comment and without a delayed effective date. 5 U.S.C. § 553(b)(B) & (d)(3).

NOTE: The CDC has advised that the best way to prevent illness is to avoid being exposed to this virus: practice social distancing; clean your hands often; cover coughs and sneezes; and call your healthcare provider if you believe you may be infected. <http://www.coronavirus.gov>.

OCR remains in close coordination with federal partners to help ensure that the Nation's response effectively addresses the needs of at-risk populations. To this end and as resources allow, government officials, health care providers, and covered entities should not overlook their obligations under federal civil rights laws to help ensure all segments of the community are served by:

- Providing effective communication with individuals who are deaf, hard of hearing, blind, have low vision, or have speech disabilities through the use of qualified interpreters, picture boards, and other means;
- Providing meaningful access to programs and information to individuals with limited English proficiency through the use of qualified interpreters and through other means;
- Making emergency messaging available in plain language and in languages prevalent in the affected area(s) and in multiple formats, such as audio, large print, and captioning, and ensuring that websites providing emergency-related information are accessible;
- Addressing the needs of individuals with disabilities, including individuals with mobility impairments, individuals who use assistive devices, auxiliary aids, or durable medical equipment, individuals with impaired sensory, manual, and speaking skills, and individuals with immunosuppressed conditions including HIV/AIDS in emergency planning;
- Respecting requests for religious accommodations in treatment and access to clergy or faith practices as practicable.

Some actions or accommodations may not be required on the basis that they may fundamentally alter the nature of a program, pose an undue financial and administrative burden, or pose a direct threat.

In addition, the Secretary's March 17, 2020, Declaration under the Public Readiness and Emergency Preparedness (PREP) Act may apply with respect to some private claims arising from the use or administration of a covered countermeasure and may provide immunity from certain liability under civil rights laws. Questions regarding the scope of PREP under this guidance document should be directed to the Office of the General Counsel.

Finally, covered entities should consider adopting, as circumstances and resources allow, the following practices to help ensure all segments of the community are served:

- Making use of multiple outlets and resources for messaging to reach individuals with disabilities, individuals with limited English proficiency, and members of diverse faith communities; and
- Stocking facilities with items that will help people to maintain independence, such as hearing aid batteries, canes, and walkers.

Being mindful of all segments of the community and taking reasonable steps to provide an equal opportunity to benefit from emergency response efforts, including making reasonable accommodations will help ensure that the emergency response is successful and minimizes stigmatization.

<https://www.cdc.gov/coronavirus/2019-ncov/about/related-stigma.html>.

For information regarding how Federal civil rights laws apply in an emergency, please visit:

<https://www.hhs.gov/civil-rights/for-individuals/special-topics/emergency-preparedness/index.html>

For information regarding Emergency Preparedness Resources for Persons from Diverse Cultural Origins,

please visit: <https://www.hhs.gov/civil-rights/for-individuals/special-topics/emergency-preparedness/diverse-cultural-origins/index.html>.

COVID-19 and HIPAA

OCR issued a bulletin on February 3, 2020, providing information on the ways that covered entities and business associates may share protected health information under the HIPAA Privacy Rule during a public health emergency.

- [February 2020 HIPAA and Novel Coronavirus Bulletin - PDF*](#)

In order to ensure that healthcare providers can serve patients, including those who cannot or should not leave their homes during this emergency, OCR [announced](#) on March 17, 2020, that it will exercise its enforcement discretion and will not impose penalties for HIPAA violations against health care providers that in good faith provide telehealth using non-public facing audio or video communication products, such as FaceTime or Skype, during the COVID-19 nationwide public health emergency. This exercise of enforcement discretion applies regardless of whether the telehealth service is related to the diagnosis and treatment of health conditions related to COVID-19. OCR also issued guidance in the form of frequently asked questions in support of the good faith rendering of telehealth services.

- [Notice of Enforcement Discretion for Telehealth](#)
- [FAQs on Telehealth and HIPAA](#)

OCR also issued guidance on when the HIPAA Privacy Rule permits a covered entity to disclose the protected health information of an individual who has been infected with, or exposed to, COVID-19, with law enforcement, paramedics, other first responders, and public health authorities without the individual's authorization.

- [Guidance on Disclosures to Law Enforcement and Other First Responders](#)

Filing a Complaint with OCR

If you believe that a covered entity violated your civil rights, conscience and religious freedom, or health information privacy rights, you may file a complaint at <https://www.hhs.gov/ocr/complaints>.

Other Resources

You may send inquiries to OCRMail@hhs.gov or call the OCR toll-free phone line at (1-800-368-1019), (TTY: 1-800-537-7697) for further information.

For a list of other Federal civil rights enforcement agencies and how to file a complaint with them, please visit: <https://www.justice.gov/crt/fcs/Agency-OCR-Offices>

For resources provided by the Administration for Community Living, please visit:
<https://acl.gov/COVID-19>

COVID-19 resources are now available in American Sign Language (ASL) on CDC's YouTube page:
<https://www.youtube.com/user/CDCStreamingHealth/videos>

To see CDC updates on COVID-19, please visit:
<https://www.cdc.gov/coronavirus/2019-ncov/whats-new-all.html>

For the U.S. Department of Education's COVID-19 statement addressing stereotyping, harassment, and bullying, please visit: <https://content.govdelivery.com/accounts/USED/bulletins/27f5130>

If you would like to learn more about Civil Rights, Conscience and Religious Freedom, the HIPAA Privacy Rule and the HIPAA Security Rule subscribe to the OCR Civil Rights Listserv at:
<https://www.hhs.gov/ocr/list-serv>.

For copies of OCR documents in alternative formats, please call (800) 368-1019 or (800) 537-7697 (TDD).

If you speak a non-English language and need help with this document, call 1-800-368-1019 (TTY: 1-800-537-7697), and you will be connected to an interpreter who will assist you at no cost.

Español (Spanish)

ATENCIÓN: Si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

- [Hojas de datos - sobre las leyes en contra de la discriminación](#)
- [Derechos sobre la confidencialidad de la información sobre su salud](#)

繁體中文 (Chinese)

注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 1 (800) 368-1019 (TTY 文字電話：1 (800) 537-7697)。

- [事實紙頁-關於反視的法律](#)
- [您的健康資訊隱私權](#)
- [您的健康信息隱私權](#)

Tiếng Việt (Vietnamese)

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

- [T Thông Tin - v các điều luật chng phân biệt x](#)
- [Quyền Bảo mật Thông tin Sức khỏe của Quý vị](#)

한국어(Korean)

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1 (800) 368-1019번 (TTY: 1 (800) 537-7697번)으로 전화하십시오.

- [정보 안내서 -- 차별 금지법에 관한 정보](#)
- [개인의 의료 정보 보호 권리](#)

Tagalog (Tagalog)

PAUNAWA: Kung nagsasalita ka ng Tagalog, may mga libreng serbisyo para sa tulong sa wika na maaari mong gamitin. Tumawag sa 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

- [Paunawa - tungkol sa mga batas laban sa diskriminasyon](#)
- [ANG IYONG MGA KARAPATAN SA PAGKAPRIBADO NG IMPORMASYONG PANGKALUSUGAN](#)

Русский (Russian)

ВНИМАНИЕ! Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните по номеру 1 (800) 368-1019 (телетайп: 1 (800) 537-7697).

- [Информационные листки о законах, запрещающих дискриминацию](#)
- [ВАШИ ПРАВА НА ЗАЩИТУ КОНФИДЕНЦИАЛЬНОСТИ МЕДИЦИНСКОЙ ИНФОРМАЦИИ](#)

العربية(Arabic)

هاتف الصم (1 (800) 368-1019 اتصل على الرقم . إذا كنت تتحدث العربية، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان :ملحوظة
والبيكم 7697-537 (800) 1)

Kreyòl Ayisyen (French Creole)

ATANSYON Si w pale Kreyòl, gen sèvis èd pou lang gratis ki disponib pou ou. Rele 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

Français (French)

ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1 (800) 368-1019 (ATS : 1 (800) 537-7697).

Português (Portuguese)

ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

Polski (Polish)

UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Dzwonić pod numer 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

- [Strony informacyjne na temat ustaw o przeciwdziałaniu dyskryminacji](#)
- [PRAWA DO OCHRONY PRYWATNOŚCI DANYCH ZDROWOTNYCH](#)

日本語 (Japanese)

注意事項：日本語を話される場合、無料の言語支援をご利用いただけます。Call 1 (800) 368-1019 (TTY:1 (800) 537-7697).

Italiano (Italian)

ATTENZIONE: In caso la lingua parlata sia l'italiano, sono disponibili servizi di assistenza linguistica gratuiti. Chiamare il numero 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

Deutsch (German)

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufen Sie uns an unter 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

Persian (Farsi)

شما می اگر به زبان فارسی صحبت می کنید، خدمات یاری رسانی زبانی، بطور رایگان، در دسترس توجه
تماس بگیرید (1 (800) 537-7697) ، 1 (800) 368-1019 با شماره باشد.

Updated: April 3, 2020