NCIL
National Council
on Independent Living

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Dear Medical Director, David Farris, MD and Members of the Oregon Medical Board,

We write this letter on behalf of the National Council on Independent Living (NCIL), a leading national disability rights organization, and the longest-running national cross-disability, grassroots organization run by and for people with disabilities. NCIL represents thousands of individuals with disabilities and organizations including Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), and other organizations that advocate for the human and civil rights of people with disabilities throughout the US.

As an organization advocating for all people with disabilities, we support policies that benefit people living with substance use disorder and people living with pain. Our work in this area began as efforts to address opioid addiction ramped up in the US, and we saw people with chronic pain left out of these efforts and harmed as a result.

We applaud the state of Oregon for improving access to non-opioid and non-pharmacological treatments for acute and chronic pain, along with better access to therapies for addiction. As addiction can be a disability, we know the devastating effects of drug misuse, fraud, and diversion. We advocate for all forms of addiction treatment, including evidence-based MOUD (Medication for Opioid Use Disorder) or MAT (Medication-Assisted Treatment). We strongly support access to non-opioid treatments and therapies for people with pain, and we advocate for development of new non-opioid alternatives.

Today, we write to share our concern regarding the Oregon Medical Board's 2021 Statement of Philosophy on Pain Management, which appears to misapply the CDC's *Guideline for Prescribing Opioids for Chronic Pain*. On November 3, 2022, the CDC released an updated 2022 *Clinical Practice Guideline for Prescribing Opioids for Pain*, which rejects one-size-fits-all approaches and strongly endorses patient-centered, individualized care.[1]

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We have previously shared concerns with the Oregon Health Authority, on behalf of our members and other people with disabilities in Oregon. Some of these individuals live with rare diseases for which there are no cures and little in the way of effective treatment beyond pain management support.

Evidence suggests a minority of people with severe chronic pain can benefit from opioid medication long-term, [1] [2] [3] and higher dosage is beneficial in some cases.[4] These individuals, the majority of whom do not meet diagnostic criteria for addiction, have become an underserved community in recent years. According to recent studies, more than 50% of clinicians are unwilling to accept patients who regularly use opioids to manage pain, [5] and 81% are reluctant to. [6]

Focus on daily dosage numbers in MME (morphine milligram equivalent) has led to ethical issues that state medical boards must address: "clinicians who are willing to care for patients on higher doses face elevated oversight risk, and this may create an incentive to discard or fail to treat some of the most vulnerable patients."[7]

The Oregon Medical Board Summer 2021 Newsletter describes opioid taper and transfer to buprenorphine therapy as "new practice standards for the safety of our patients." The Board's Statement of Philosophy on Pain Management advises: "not all patients can be tapered to MED less than 90… As much as possible, patients should be transitioned to Medication-Assisted Treatment (MAT)."

Taken together, these statements would seem to imply that disrupting stable long-term therapy is an expected standard of care in Oregon. These statements do not represent consensus in the medical community nationwide, given the gaps and limitations in evidence, the diversity of conditions generating severe long-term pain, and studies

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[1] Bialas P**[1]**, Maier C**[2]**, Klose P**[3]**, Häuser W. Efficacy and harms of long-term opioid therapy in chronic non-cancer pain: Systematic review and meta-analysis of open-label extension trials with a study duration ≥26 weeks. Eur J Pain. 2019 Oct 29. doi: 10.1002/ejp.1496

[2] Noble M, Treadwell JR, Tregear SJ, et al. Long-term opioid management for chronic noncancer pain. Cochrane Database Syst Rev. 2010;(1):CD006605.

[3] Farrar, John T.[a,*]; Bilker, Warren B.[a]; Cochetti, Philip T.[a]; Argoff, Charles E.[b]; Haythornthwaite, Jennifer[c]; Katz, Nathaniel P.[d]; Gilron, Ian[e] Evaluating the stability of opioid efficacy over 12 months in patients with chronic noncancer pain who initially demonstrate benefit from extended release oxycodone or hydrocodone: harmonization of Food and Drug Administration patient-level drug safety study data, PAIN: January 2022 - Volume 163 - Issue 1 - p 47-57 doi: 10.1097/j.pain.0000000000002331

[4] Beth Darnall, PhD, "Evolution of Opioid Tapering and Challenges," NIH HEAL Workshop 6/1/20, https://heal.nih.gov/files/2020-06/Darnall_NIH_HEAL_060120.pdf

[5] Lagisetty, P.; Macleod, C.; Thomas, J.; Slat, S.; Kehne, A.; Heisler, M; Bohnert, A.; Bohnert, K., *Assessing reasons for decreased primary care access for individuals on prescribed opioids, an audit study*, PAIN (Nov. 11, 2020), https://journals.lww.com/pain/Abstract/9000/Assessing_reasons_for_decreased_primary_care.98202.aspx. *See also* https://labblog.uofmhealth.org/industry-dx/pain-patients-who-take-opioids-cant-get-door-at-half-of-primary-care-clinics (Jan. 25, 2021).

[6] Quest Diagnostics and Center for Addiction, HealthTrends, *Drug Misuse in America: Physician Perspectives and Diagnostic Insights on the Evolving Drug Crisis* (2019) https://questdiagnostics.com/home/physicians/health-trends/trends/pdm-health-trends.html

[7] Nicholson, K. and Hellman, D., Opioid Prescribing and the Ethical Duty to *Do No Harm* (May 27, 2020), 46 Am. J.L. & Med., Forthcoming June 2020; Virginia Public Law and Legal Theory Research Paper No. 2020-48. Available at SSRN: https://ssrn.com/abstract=3611753

showing grave risks associated with opioid dosage reduction.[8] [9] [10] [11] International experts in pain and addiction have warned that disrupting stable long-term therapy can destabilize lives, resulting in worsening pain, profound loss of function, and life-threatening harm.[12] [13]

While voluntary, supported opioid tapering can improve life for some people with chronic pain,[14] tapering imposes grave risks on others. Findings from numerous studies, including a new study published in August 2022, "do not support opioid dosage tapering as a strategy to reduce harms for patients receiving stable long-term opioid therapy without evidence of misuse."[15]

Research suggests that reducing dose increases overdose risk more than continuing a high dosage.[16] Those who taper dosage, even gradually, face increased risk of harm. While some do eventually stabilize, new studies show the overall risk of harm associated with taper does not diminish over time, even years later.[17]

Serious harms from tapering are highlighted in a 2019 FDA safety warning,[18] an open letter to the CDC from over 300 health professionals and three former White House

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[8] Mark, T, Parish, W., Opioid medication discontinuation and risk of adverse opioid-related health care events, https://pubmed.ncbi.nlm.nih.gov/31079950

[9] Agnoli A, Xing G, Tancredi DJ, Magnan E, Jerant A, Fenton JJ. Association of Dose Tapering With Overdose or Mental Health Crisis Among Patients Prescribed Long-term Opioids. *JAMA.* 2021;326(5):411–419. doi:10.1001/jama.2021.11013

[10] James, J.R., Scott, J.M., Klein, J.W. et al. Mortality after discontinuation of primary care-based chronic opioid therapy for pain: a retrospective cohort study. J GEN INTERN MED (2019) 34: 2749. https://doi.org/10.1007/s11606-019-05301-2

[11] Oliva EM, Bowe T, Manhapra A, et al. Associations between stopping prescriptions for opioids, length of opioid treatment, and overdose or suicide deaths in US veterans: observational evaluation. *BMJ.* 2020;368:m283.

[12] Darnall, B.,et al. International Stakeholder Community of Pain Experts and Leaders Call for an Urgent Action on Forced Opioid Tapering**,** *Pain Medicine***,** Volume 20, Issue 3, March 2019, Pages 429–433, https://doi.org/10.1093/pm/pny228

[13] Kertesz, Stefan, MD, MSc, Ajay Manhapra, MD, and Adam J. Gordon, MD MPH FACP DFASAM CMRO, "What's Wrong With Just Counting the Patients on High Dose Opioids and Calling that Bad Care? (3 addiction docs respond to CMS)," February 9, 2018. https://medium.com/@StefanKertesz/whats-wrong-with-just-counting-the-patients-on-high-dose-opioids-and-calling-that-bad-care-3f585ceac22e

[14] Beth D Darnall, PhD, et al, Comparative Effectiveness of Cognitive Behavioral Therapy for Chronic Pain and Chronic Pain Self-Management within the Context of Voluntary Patient-Centered Prescription Opioid Tapering: The EMPOWER Study Protocol**,** *Pain Medicine***,** Volume 21, Issue 8, August 2020, Pages 1523–1531, https://doi.org/10.1093/pm/pnz285

[15] Larochelle MR, Lodi S, Yan S, Clothier BA, Goldsmith ES, Bohnert ASB. Comparative Effectiveness of Opioid Tapering or Abrupt Discontinuation vs No Dosage Change for Opioid Overdose or Suicide for Patients Receiving Stable Long-term Opioid Therapy. *JAMA Netw Open.* 2022;5(8):e2226523. doi:10.1001/jamanetworkopen.2022.26523

[16] Glanz JM, Binswanger IA, Shetterly SM, Narwaney KJ, Xu S. Association Between Opioid Dose Variability and Opioid Overdose Among Adults Prescribed Long-term Opioid Therapy. *JAMA Netw Open.* 2019;2(4):e192613. doi:10.1001/jamanetworkopen.2019.2613

[17] DiPrete BL, Ranapurwala SI, Maierhofer CN, et al. Association of Opioid Dose Reduction With Opioid Overdose and Opioid Use Disorder Among Patients Receiving High-Dose, Long-term Opioid Therapy in North Carolina**.** *JAMA Netw Open.* 2022;5(4):e229191. doi:10.1001/jamanetworkopen.2022.9191

[18] United States Food and Drug Administration. "FDA identifies harm reported from sudden discontinuation of opioid pain medicines and requires label changes to guide prescribers on gradual, individualized tapering," FDA Drug Safety Communication, 4/9/19. https://www.fda.gov/drugs/drug-safety-and-availability/fda-identifies-harm-reported-sudden-discontinuation-opioid-pain-medicines-and-requires-label-changes

drug czars,[19] and a report from the international watchdog organization Human Rights Watch.[20]

To address these harms, the CDC clarified in 2019 that clinicians should "taper or reduce dosage *only* when patient harm outweighs patient benefit of opioid therapy."[21] The updated 2022 *CDC Guideline* includes an expanded warning: "Because tapering opioids can be harmful in some circumstances, benefits of continuing opioids in patients who have already received them long-term might include avoiding risks of tapering and discontinuing opioids." An ideologically diverse panel of experts noted "[i]t is acceptable to continue higher than recommended doses of LTOT when there are neither adverse effects nor aberrant behaviors and the patient demonstrates functional and analgesic benefits."[22] The U.S. Department of Health and Human Services agreed: "the balance of benefit and risk for doses above 90 Morphine Milligram Equivalents (MME)/day may be acceptable in some patients."[23]

As the American Medical Association wrote in November 2018: "no entity should use MME (morphine milligram equivalents) as anything more than guidance, and physicians should not be subject to professional discipline, loss of board certification, loss of clinical privileges, criminal prosecution, civil liability, or other penalties or practice limitations solely for prescribing opioids at a quantitative level above the MME thresholds found in the *CDC Guideline for Prescribing Opioids for Chronic Pain.*"[24]

The 2022 *CDC Guideline* echoes AMA's recommendation: "Payers, health systems, and state medical boards should not use this clinical practice guideline to set rigid standards or performance incentives related to dose or duration of opioid therapy." Performance incentives related to dose, in particular, risk grave harm to our community.

The CDC's and AMA's cautionary statements are further supported by recent research showing that MMEs are often calculated using flawed methods; the same medication at the same interval could be calculated as having an MME that falls below or above the 50-90 MME range.[25]

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[19] *See CDC Response Letter* from Robert R. Redfield on Health Professionals for Patients in Pain (HP3) website, https://healthprofessionalsforpatientsinpain.org/press-release

[20] Human Rights Watch. Report, *Not Allowed to be Compassionate* (Dec. 2018), https://www.hrw.org/report/2018/12/18/not-allowed-be-compassionate/chronic-pain-overdose-crisis-and-unintended-harms-us

[21] Letter from CDC Director Robert Redfield, April 10, 2019 https://static1.squarespace.com/static/54d50ceee4b05797b34869cf/t/5caf661d7f312b0001bac1b8/1554998814907/Alford+Final+.pdf

[22] Covington, Edward C. et al. "Ensuring Patient Protections When Tapering Opioids: Consensus Panel Recommendations." Mayo Clinic Proceedings, Volume 95, Issue 10, 2155 – 2171. https://doi.org/10.1016/j.mayocp.2020.04.025

[23] Final Report, Pain Management Best Practices Inter-Agency Task Force: Updates, Gaps, Inconsistencies, and Recommendations, May 23, 2019, https://www.hhs.gov/sites/default/files/pmtf-final-report-2019-05-23.pdf.

[24] American Medical Association, Resolution 235, "Inappropriate Use of CDC Guidelines for Prescribing Opioids," passed by the AMA House of Delegates, November 13, 2018.

[25] Dasgupta, Nabarun PhD; Wang, Yanning MS; Bae, Jungjun BS; Kinlaw, Alan C. PhD; Chidgey, Brooke A. MD; Cooper, Toska MPH; Delcher, Chris PhD. Inches, Centimeters, and Yards, The Clinical Journal of Pain: August 2021 - Volume 37 - Issue 8 - p 565-574 doi: 10.1097/AJP.0000000000000948

Treatment for any medical condition should be based on an evaluation of potential benefits versus potential harms for each individual independently. By describing taper as an expected standard of care, the Board exposes people with disabilities to *more* risk, in the name of safety.

According to Dr. Beth Darnall, Associate Professor of Anesthesiology, Perioperative and Pain Medicine at Stanford University and director of the Stanford Pain Relief Innovations Lab. "[w]e risk the greatest harm by destabilizing individuals, both medically and psychologically, and that is the inflection point we must address."

Regarding terminal illness, the Board rightly notes that "fear on the part of physicians may result in inadequate pain control and unnecessary suffering." In a state where nearly 33% of recipients of assisted suicide cite inadequate pain control as a factor in their decision to end their lives, harms from tapering should be particularly concerning to the Board.

Someone who is tapered off opioid analgesics, yet loses their life to suicide from untreated pain or loses ability to work or function, is not a success. Reduced prescribing alone should not be a measure of success. Success must include improved well-being, improved function, and quality of life with positive long-term outcomes.

Medical licensing boards in other states have made progress to protect against harmful tapering practices. The Washington Medical Commission advises clinicians to initiate opioid taper only under specific circumstances. Encouraging or requiring a clinician to taper all long-term opioid therapy incentivizes below-standard care: "Ending opioid therapy or initiating a forced tapering of opioids to a particular MED level for reasons outside of clinical efficacy or improvement in quality of life and/or function or abuse would violate the intent of the rules." The State of Washington specifies standard of care in cases where "the practitioner initiates a tapering schedule without consent of the patient or consideration of function or quality of life. This would be a clear violation of the Commission opioid prescribing rules."[26]

Similarly, new draft prescribing guidelines by the Medical Board of California state that while taper may be offered on a trial basis, "[t]aper trials are considered successful if treatment decisions are individual and based on the patient's response to the last dose change," also noting that the recommendation to document a decision to prescribe more than 90 MME/day "is not intended to be used as a limitation on prescribing or as a rigid standard of care." [27] As the Board guides clinicians, "[t]here is the fraction of patients who are likely benefiting from opioids and a dosage reduction makes their pain worse, increasing their difficulty in weaning. For these patients, the benefits of opioid therapy may outweigh risks and continued stable opioid therapy may be the best course of action."

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[26] Washington Medical Commission, Notice of Adoption of Interpretive Statement, March 8, 2019, https://wmc.wa.gov/sites/default/files/public/documents/Opioid-PatientsINS2019-02.pdf

[27] Medical Board of California, "Guidelines for Prescribing Controlled Substances for Pain," July 2022 draft, https://www.mbc.ca.gov/About/Meetings/Material/31002/ip-AgendaItem4-20220714.pdf

The State of New Hampshire Board of Medicine removed MME thresholds from their opioid prescribing rules in August 2021. Beginning in August 2022, Minnesota law prohibits clinicians treating intractable pain from tapering dosages solely to meet particular MME thresholds. The Texas Medical Board advises clinicians to "use extra caution" and "strongly consider referring the patient to a pain specialist" for prescriptions above 90 MME/day, while noting "if the benefits outweigh the risks, there is no need to discontinue the therapy…. It's important to remember that there is no "one size fits all" approach to treating pain and each patient is unique."[28]

We believe the Oregon Medical Board also diverges from national consensus in use of the term "MAT (Medication-Assisted Treatment)" to refer to therapy for pain. As noted by experts on tapering, "for patients taking opioids as prescribed, difficulty with tapering alone is insufficient evidence for a DSM-5 opioid use disorder diagnosis."[29] Failure of attempted taper is not necessarily a sign of opioid use disorder. Rather, failure of attempted taper may indicate that benefits of opioid medication were greater than previously estimated. Being disinclined to voluntarily attempt taper is understandable, if loss of function post-taper could result in misdiagnosis with, or discrimination based on, a perceived disability (Substance Use Disorder) they do not actually have.

The OMB's newsletter references prescribing guidelines written by Oregon Pain Guidance, which is not an official government entity, and therefore not subject to oversight or public input. The Oregon Health Authority's Opioid Prescribing Guidelines and Taper Guidelines would be better references for a state agency to cite, as these have been through the public comment process with oversight.

The OMB's Statement of Philosophy on Pain Management also influences disciplinary plans imposed on clinicians. As recently as April 2023, the Board has ordered certain clinicians to discharge, transfer, or taper all patients on long-term opioid therapy to a target dosage of 90 MME, disregarding the individual risk/benefit balance for each person. Such orders by the Board expose people with disabilities to grave risk of harm.

According to the 2022 *CDC Guideline*, tapering opioids should be a risk/benefit calculation for each individual, never a standing order for all: "Clinicians should carefully weigh both the benefits and risks of continuing opioid medications and the benefits and risks of tapering opioids…. Because tapering opioids can be harmful in some circumstances, benefits of continuing opioids in patients who have already received them long-term might include avoiding risks of tapering and discontinuing opioids." [30]

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[28] TMB Bulletin, December 2018. https://www.tmb.state.tx.us/dl/3117856E-9DE9-FDD8-A22C-9C7CB3FAC715

[29] Darnall, Beth D.[a,*]; Fields, Howard L.[b] Clinical and neuroscience evidence supports the critical importance of patient expectations and agency in opioid tapering, PAIN: May 2022 - Volume 163 - Issue 5 - p 824-826 doi: 10.1097/j.pain.0000000000002443

[30] Dowell D, Ragan KR, Jones CM, Baldwin GT, Chou R. CDC Clinical Practice Guideline for Prescribing Opioids for Pain — United States, 2022. MMWR Recomm Rep 2022;71(No. RR-3):1–95. DOI: http://dx.doi.org/10.15585/mmwr.rr7103a1

Furthermore, studies showing successful taper and/or transfer to buprenorphine have high dropout rates, limiting the applicability and generalizability of the results.[31]

When Oregonians with long-term opioid prescriptions need a new clinician, they have found it extremely difficult (if not impossible) to locate other clinicians willing to accept them. Some of our members (among many others) have lost access to the full spectrum of available and effective pain treatments, or lost access to medical care altogether.

Physicians have a duty to relieve suffering and not to abandon patients,[32] especially at a critical juncture in care when harm may result. Physicians also have responsibilities under the Americans with Disabilities Act not to turn away patients on the basis of their disability[33] – including chronic pain – or the medication that patients take.[34]

We urge the Oregon Medical Board to end the use of numerical dosage targets that misapply federal guidelines. Guidelines applied across entire populations must allow for unusual cases, exceptions, and outliers, particularly in cases where other treatments have failed. Failure to sufficiently account for outliers may be, in effect, discrimination on the basis of disability.

Since 2012 the nation has experienced a dramatic decline in opioid prescribing, which (according to the most recent IQVIA data) is currently below that of the year 2000,[35] with no corresponding reduction in overdose deaths. [36] In the end, "[t]he ultimate test of policy change in health care is not whether prescription use can be reduced (as is now the case in every state), but how we can ensure safety and functioning of the people whose lives are affected."[37]

We thank you for considering perspectives from the disability community. Questions and comments may be directed to Jessica Podesva, Director of Advocacy and Public Policy, (jessica@ncil.org).

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[31] Sturgeon JA, Sullivan MD, Parker-Shames S, Tauben D, Coelho P. Outcomes in Long-term Opioid Tapering and Buprenorphine Transition: A Retrospective Clinical Data Analysis. Pain Med. 2020 Dec 25;21(12):3635-3644. doi: 10.1093/pm/pnaa029. PMID: 32163149.

[32] CODE OF MED. ETHICS Opinion 1.1.2, Am. Med. Ass'n, https://www.ama-assn.org/sites/ama-assn.org/files/corp/media-browser/code-of-medical-ethics-chapter-1.pdf (discussing ethical obligation not to decline patients whom they've accepted into care).

[33] Americans with Disabilities Act of 1990 (Title III), 42 U.S. Code § 12181-9, 28 C.F.R. part 26 (title III); Bragdon v. Abbott, 524 U.S. 624 (1998) (refusal of dentist to treat patient on the basis of HIV disease violates ADA).

[34] Settlement Agreement Between U.S. Department of Justice and Selma Medical (resolving violations of the ADA related to the refusal to accept a prospective new patient on the basis that he takes Suboxone), https://www.justice.gov/opa/pr/justice-department-reaches-settlement-selma-medical-associates-inc-resolve-ada-violations

[35] IQVIA Institute Report, *Prescription Opioid Trends in the United States, Measuring and understanding process in the opioid crisis* (Dec. 16, 2020), https://www.iqvia.com/insights/the-iqvia-institute/reports/prescription-opioid-trends-in-the-united-states

[36] Stefan G. Kertesz, MD, MSC, "Opioid Correction vs. Opioid Trauma: Where Policy Meets Chronic Pain," https://slideplayer.com/slide/16003420/

[37] Mackey, Sean MD, PhD. "Pain and Addiction Leaders Raise Alarm on Oregon Force Tapering Opioid Proposal." www.drseanmackey.com 3 Mar 2019, https://secureservercdn.net/198.71.233.138/b2m.8e8.myftpupload.com/wp-content/uploads/2019/11/OregonHERC3-7-2019ws.pdf

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