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June 25, 2019

The Honorable Mitch McConnell
Majority Leader, United States Senate

The Honorable Charles Schumer
Minority Leader, United States Senate

The Honorable Nancy Pelosi
Speaker of the United States House of Representative

The Honorable Kevin McCarthy
Minority Leader, United States House of Representatives

The Honorable Lamar Alexander
Chair, Senate HELP Committee

The Honorable Patty Murray
Ranking Member, Senate HELP Committee

The Honorable Frank Pallone
Chair, House Energy and Commerce Committee

The Honorable Greg Walden
Ranking Member, House Energy and Commerce Committee

Dear Senator McConnell, Senator Schumer, Representative Pelosi,
Representative McCarthy, Senator Alexander, Senator Murray,
Representative Pallone, and Representative Walden,

We write this letter today on behalf of the undersigned disability rights organizations. As organizations that advocate for the civil and human rights of people with disabilities, we are highly concerned about access to appropriate treatment for both people with addiction and people in serious pain, as both pain and addiction may be disabilities under the Americans with Disabilities Act (ADA).

We appreciate Congress' work on legislation to address opioid addiction and overdoses. We are, however, alarmed that as efforts to address opioid addiction have moved forward, the needs of people with serious pain have been addressed inappropriately or left out entirely.

Indeed, many policies are actually erecting new barriers to pain treatment -- barriers that leave people with disabilities and serious health conditions unable to access pain medication, or result in people being tapered forcibly or abruptly off of their medications or abandoned in care entirely -- often with devastating results. These policies and the resulting harms were addressed in April by Centers for Disease Control and Prevention (CDC),ⁱ the Food and Drug Administration (FDA),ⁱⁱ and the Pain Management Best Practices Inter-Agency Task Force that was created by the Comprehensive Addiction and Recovery Act of 2016 (Inter-Agency Task Force).ⁱⁱⁱ

Background

Policies focused narrowly on redressing addiction and overdose deaths through limiting opioid prescriptions have proliferated at an alarming pace in the past three years. They have been enacted into law in over half of U.S. states^{iv}, adopted by the major pharmacy chains and both public and private payers, and proposed in two pending federal bills. These policies derive from the CDC's 2016 Guideline for Prescribing Opioids for Chronic Pain.^v Nevertheless, the CDC recently stated publicly and unequivocally that such policies, which apply its recommendations as hard limits rather than with the clinical flexibility the guideline espouses, are – in fact – ***inconsistent with the Guideline and risk harm to patient health and safety.***^{vi}

This harm has been highlighted in a report from the international watchdog organization, Human Rights Watch (HRW),^{vii} a letter to the CDC from over 300 health professionals and three former White House drug czars^{viii}, a widely-publicized international stakeholder letter^{ix} and, recently, the CDC, the Inter-Agency Task Force and the FDA. People with chronic pain may deteriorate medically, lose their ability to function or work, or resort to suicide or illegal substances when their medication is denied.

People with disabilities, who already face barriers to receiving healthcare on an equal basis to others, have experienced these burdens profoundly. Individuals with disabilities disproportionately experience serious pain, and some use opioids to manage pain from serious or incurable conditions.^x The research correlating pain and disability is extensive: long-term pain is one of the primary causes of disability worldwide and in the US, and pain is a primary feature in many disabling conditions.^{xi} Recent studies show that nearly 20 million Americans experience pain that interferes with their ability to engage in basic life activities, a common definition of disability.^{xii}

One-sized Policymaking

The types of one-size-fits-all policy approaches to limiting opioid prescribing which the CDC considers a misapplication of its guideline include the following:

- **Strict limits to opioid prescribing for acute pain, often of 3-7 days.**

Drawn from a single sentence in a guideline about prescribing for chronic, not acute, pain, these duration limits now exist in most major payer and pharmacy policies and state laws. They are also the basis of two proposed federal laws. A primary reason for the CDC's warning against this sort of strict application by policymakers is the limited state of available evidence for some of its recommendations. This recommendation was rated evidence quality 4, or having poorest evidentiary support: "type 4 evidence indicates that one has very little confidence in the effect estimate, and the true effect is likely to be substantially different from the estimate").^{xiii}

The FDA is in the process of developing detailed, evidence-based guidelines focused specifically on the different types of acute pain.^{xiv} Further policy developments on this issue should await its findings.

- **Strict application of dosage guidance from the CDC's guideline.**

The CDC guideline contains dosage guidance to assist doctors in starting a new, opioid-naïve individual ranging from the equivalent of 50 to 90 milligrams of morphine a day. This recommendation is also based on low quality evidence (evidence quality 3).^{xv}

Yet this dosage guidance has taken on a life of its own, becoming, as the CDC recently recognized, a sort of benchmark or proxy for safe prescribing.^{xvi} It has been translated as a de facto limit into pharmacy and payer policies, and has been used to flag patients as over-utilizers and physicians as over-prescribers, without any consideration of the context of an individual's disease or the population of individuals a physician treats.

As CDC Director Redfield recently clarified, this provision was never intended to apply to people currently taking opioids—as the implications of altering medication for current patients are quite different. For current patients, the Director makes clear, the only relevant question is whether the benefits exceed the risks of the medication.^{xvii} The final report released by the Interagency Task Force also criticized the strict use of dosage thresholds as unscientific and potentially harmful.^{xviii}

Nevertheless these numbers are now used in risk scoring algorithms by payers, hospitals, pharmacies and law enforcement agencies, often in ways that are non-transparent. Higher-than-average dosage may automatically generate a "high-risk" score, even for individuals who have had years of successful long-term therapy and who exhibit no other risk factors,^{xix} and may lead to the abrupt and inappropriate denial of medication.

Unintended Consequences that Risk Patient Safety

The policies derived from the CDC Guideline have had unintended consequences that risk harm to patient safety, including:

- **Mandatory or abrupt tapering of individuals off of opioids and patient abandonment**

According to a report issued by Human Rights Watch, the misapplication of the CDC's dosage threshold has resulted in doctors fearing that prescribing at higher doses will expose them to liability. This fear has led physicians to forcibly reduce or discontinue their patients' opioids, even when they believed their patients were benefitting from the therapy.^{xx} Both Human Rights Watch and the Interagency Task Force describe a rise in pain patient abandonment by clinicians – even among people with long-term pain who do not use opioids.

There is little evidence to support forced or precipitous tapering and growing evidence that it carries grave risks of harm^{xxi}. Recent studies suggest that even destabilizing the dosage of a current patient may result in a fourfold increase their likelihood to suffer opioid-related death,^{xxii} and that many people are tapered abruptly,^{xxiii} a practice the FDA recently came out strongly against citing reports of serious harm that includes increased pain, psychological distress and suicide.^{xxiv} The CDC Director made clear that the guideline “does not endorse mandated or abrupt dose reduction or discontinuation,” also noting that “these actions can result in patient harm.”^{xxv}

- **Overreach to unintended populations**

Another unintended consequence of misapplications of the guideline has been overreach to individuals who were never intended to be covered, such as people with cancer or sickle cell disease who were expressly exempt from the CDC guideline but have experienced serious barriers to receiving medication in the current policy environment.^{xxvi} Similarly, some policies focused on acute pain have exempted people with chronic pain, but these exemptions too have proven insufficient to protect access to medication.

Another recent statement from the CDC states that the guideline was never intended to apply to people with cancer or sickle cell nor to deny access to opioid analgesics *for anyone with chronic pain*.^{xxvii} The CDC and all professional guidelines caution doctors not to use opioids as a first or second line of treatment, but all provide for access to opioid analgesia where people are properly screened and other treatment modalities have failed.

The Changing Environment

Opioid prescribing has dropped dramatically: the number of prescriptions dispensed at pharmacies is at a 15-year low^{xxviii}. Moreover, doctors are now much more reluctant to prescribe an opioid to someone who hasn't been exposed to them.^{xxix} At this juncture and to avoid further harm, responsible prescribing that prioritizes individualized treatment over one-size-fits-all limits should be encouraged.

The Need for Comprehensive Care

Finally, although some individuals with disabilities use opioids to manage their pain, no single treatment modality is effective for everyone; rather it is often a combination of treatments that allows individuals to most effectively manage their pain. For this reason, access to the full spectrum of available treatment modalities is essential. Yet as the Inter–Agency Task Force report found, significant administrative and logistical barriers to the treatment of pain in a multidisciplinary or integrative way exist in the current healthcare system. Although we have reduced opioid prescribing, there has not been a responsive increase in access to or coverage of non-opioid treatment, and people in pain suffer as a result. Our policies need to focus on implementing the road maps for increasing comprehensive care that have been recommended by the Inter-Agency Task Force and in the National Pain Strategy.^{xxx}

In conclusion, pain and addiction are distinct problems, but the way in which they have intersected in our recent history suggests that, if we are to avoid future emergencies, policies addressing the crisis should consider and comprehensively address both conditions, which are the prevalent, under-treated, and misunderstood public health issues of our time. As we navigate this terrain, those who promulgate laws and policies need to consider the input of people with lived experience and include people with disabilities who are too often left out of policy discussions. Despite the strong correlation between serious pain and disability in all population level research, for example, persons with disabilities were omitted as a population warranting special consideration from the recent Inter-Agency Task Force report, despite having been included in the 2016 National Pain Strategy.

We, the undersigned organizations, urge you to take our concerns and recommendations into account and to work with us. Please feel free to contact: Kate Nicholson (Kate@katenicholson.com) and Lindsay Baran (Lindsay@ncil.org), Co-Chairs of the National Council on Independent Living (NCIL) Chronic Pain/ Opioids Task Force.

Sincerely,

National Organizations

National Council on Independent Living

ADAPT

American Association of People with Disabilities

American Association on Intellectual and Developmental Disabilities

American Physical Therapy Association

Association of Programs for Rural Independent Living

Association of University Centers on Disability

Autistic Self Advocacy Network

Autistic Women & Nonbinary Network

Bazelon Center for Mental Health Law

Bloom's Connect

Center for Public Representation

Disability Rights Education & Defense Fund
DQIA Disabled Queers In Action
Healthcare Rights Coalition
Justice in Aging
National Rehabilitation Association
Not Dead Yet
Paralyzed Veterans of America
Partnership for Inclusive Disaster Strategies
Radical Abolitionist: A Cognitive Liberty Blogspace
RespectAbility
Self Advocates Becoming Empowered
Survivors Empowered Action Fund
TASH
The Arc of the United States
The Heumann Perspective

State & Local Organizations

Arizona

Ability360
Counseling DIRECTIONS
DIRECT Center for Independence

California

Independent Living Center of Southern California
Service Center for Independent Life (SCIL)

Colorado

Atlantis ADAPT
Atlantis Community, Inc.
Colorado Cross-Disability Coalition
Southwest Center for Independence

Florida

Democratic Disability Caucus of Florida

Georgia

GA ADAPT

Hawaii

Aloha Independent Living Hawaii

Idaho

LINC
Living Independently for Everyone

Illinois

Access Living
Chicago ADAPT
Disability Resource Center
IMPACT CIL
Progress Center for Independent Living
Statewide Independent Living Council of Illinois

Iowa

Disabilities Resource Center of Siouxland

Kansas

3 Rivers Inc.
Prairie Independent Living Resource Center, Inc. (PILR)
Topeka Independent Living Resource Center, Inc.

Kentucky

Center for Accessible Living

Maine

Needlepoint Sanctuary

Maryland

The IMAGE Center of Maryland

Massachusetts

Boston Center for Independent Living
Disability Policy Consortium of Massachusetts
Independence Associates, Inc.

Minnesota

Minnesota Statewide Independent Living Council

Mississippi

Living Independence for Everyone

New Jersey

Alliance Center for Independence

Nevada

Southern Nevada Center for Independent Living

New York

Center for Disability Rights
Finger Lakes Independence Center

North Carolina

Pathways For The Future, Inc.

Oregon

Eastern Oregon Center for Independent Living
Oregon State Independent Living Council

Pennsylvania

Pennsylvania Council on Independent Living

South Carolina

Disability Resource Center (dba) AccessAbility

Texas

Houston Center for Independent Living
Panhandle Independent Living Center
REACH Resource Centers on Independent Living- Fort Worth, Dallas, Denton & Plano
Texas Democrats with Disabilities

Vermont

Vermont Center for Independent Living
Vermont Coalition for Disability Rights
State Rehabilitation Council Advocacy Outreach and Education Committee
Vermont Psychiatric Survivors, Inc.

Virginia

Appalachian Independence Center, Inc.
Blue Ridge Independent Living Center
disAbility Resource Center of the Rappahannock Area, Inc.
Eastern Shore Center for Independent Living
Endependence Center
Independence Empowerment Center
Lynchburg Area Center for Independent Living Inc.
New River Valley Disability Resource Center
Resources for Independent Living Inc.
Valley Associates for Independent Living
Virginia Association of Centers for Independent Living

Washington

Spokane Center for Independent Living
Washington ADAPT

Washington, D.C.

DC Metro ADAPT

West Virginia
Mountain State Centers for Independent Living

Wisconsin
IndependenceFirst
Wisconsin Coalition of Independent Living

cc: Senate HELP Committee
House Energy & Commerce Committee

ⁱ Dowell, D., Haegerich, T., and Chou, R., “No Shortcuts to Safer Opioid Prescribing,” *New England Jol.*, April 24, 2019, <https://www.nejm.org/doi/full/10.1056/NEJMp1904190>

ⁱⁱ FDA Safety Announcement, FDA Identifies Harm Reported from Sudden Discontinuation of Opioid Pain Medicines and Requires Label Change to Guide Prescribers on Gradual, Individualized Tapering, April 9, <https://www.fda.gov/drugs/drug-safety-and-availability/fda-identifies-harm-reported-sudden-discontinuation-opioid-pain-medicines-and-requires-label-changes>

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

^{iv} Davis, C, Lieberman, A, Hernandez-Delagato, H and Suba, C, Laws Limiting the Prescribing or Dispensing of Opioids for Acute Pain in the United States: A National Systemic Legal Review, Drug and Alcohol Dep. (2019), <https://www.sciencedirect.com/science/article/pii/S0376871618307701>

^v Dowell, D., Haegerich, T. and Chou, R., Recommendations and Reports, MMWR, March 18, 2016, https://www.cdc.gov/mmwr/volumes/65/rr/rr6501e1.htm?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fmmwr%2Fvolumes%2F65%2Frr%2Frr6501e1er.htm

^{vi} *supra* note i.

^{vii} Not Allowed to Be Compassionate: Chronic Pain, The Overdose Crisis and Unintended Harms in the US, Human Rights Watch Report, December 18, 2018, <https://www.hrw.org/report/2018/12/18/not-allowed-be-compassionate/chronic-pain-overdose-crisis-and-unintended-harms-us>

^{viii} Allford, D., Dart, R., DeMicco, J., Kertesz, S., Satel, S., et al., Letter, Health Professionals for Patients In Pain, March 6, 2019. <https://healthprofessionalsforpatientsinpain.org/the-letter-1>

^{ix} Darnall, B., Jurrlink, D., Kerns, R., et al., International Stakeholder Community of Pain Experts and Leaders Call for Urgent Action on Forced Opioid Tapering, Pain, <https://academic.oup.com/painmedicine/article/20/3/429/5218985>

^x Although it is a greater consideration than we once believed, evidence continues to indicate that opioid use disorder and opioid misuse occur in a relatively small minority of patients receiving opioids for chronic pain. See Edlund M., Martin B., Russo J., DeVries A., Braden J., and Sullivan M., The role of opioid prescription in incident

opioid abuse and dependence among individuals with chronic noncancer pain, Clin. J. Pain, <https://www.ncbi.nlm.nih.gov/pubmed/24281273>, and Volkow, N., McLellan, A., Opioid Abuse in Chronic Pain – Misconceptions and Mitigation Strategies, New England Jol. (2016), <https://pdfs.semanticscholar.org/3013/5d7758acf3a0b7ee42da85617a252cbea2ed.pdf>. National studies on drug and alcohol use suggest that the vast majority of misuse is not by those who were a direct recipient of pain medication from a doctor. See, e.g., Results from the National Survey on Drug Use and Health: Detailed Tables. Retrieved from <https://www.samhsa.gov/data/data-we-collect/nsduh-national-survey-drug-use-and-health>

^{xi} Sutherland, S., Not All Pain is the Same: Characterizing the Extent of High Impact Pain, Pain Research Forum, (2019), <https://www.painresearchforum.org/news/114939-not-all-pain-same-characterizing-extent-high-impact-chronic-pain>

^{xii} Dahlhamer, J., Lucas, J., Zelaya, C. et al., Prevalence of Chronic Pain and High Impact Chronic Pain Among Adults - United States, MMWR (2016), <https://www.cdc.gov/mmwr/volumes/67/wr/mm6736a2.htm>

^{xiii} *supra* note v.

^{xiv} FDA Goals for the Committee on Evidence-Based Opioid Prescribing for Acute Pain, National Academies of Science, Engineering and Medicine, February 4, 2019, <http://nationalacademies.org/hmd/~media/Files/Activity%20Files/MentalHealth/OpioidRxGuidelines/Feb%202019%20workshop/Presentation/Throckmorton.pdf>

^{xv} *supra* note v.

^{xvi} *supra* note i.

^{xvii} Letter from CDC Director Robert R. Redfield to Daniel P. Alford, April 10, 2019, <https://img1.wsimg.com/blobby/go/3d70257f-a143-4a5b-b9df-f7d265df0d3d/downloads/Alford%20Final%20.pdf?ver=1556148791199>

^{xviii} *supra* note iii.

^{xix} Appriss NarxCare documentation, <https://northcarolina.pmpaware.net/narx-content/content/narxcare2/explain-overdose-risk-score.pdf>

^{xx} *supra* note vii.

^{xxi} Dowell, D. & Haegerich, T., Changing the Conversation About Opioid Tapering. Ann Intern Med (2017), <https://www.ncbi.nlm.nih.gov/pubmed/28715842>

^{xxii} Glanz J., Binswanger I., Shetterly S., Narwaney K, Xu S, Association Between Opioid Dose Variability and Opioid Overdose Among Adults Prescribed Long-term Opioid Therapy, JAMA Netw Open. (2019), <https://www.ncbi.nlm.nih.gov/pubmed/31002325>

^{xxiii} Mark, T., Parish, W., Opioid Medication Discontinuation and Risk of Adverse Opioid-Related Health Events, J Subst Abuse Treat., (2019), <https://www.ncbi.nlm.nih.gov/pubmed/31079950>

^{xxiv} *supra* note ii.

^{xxv} *supra* note xix.

^{xxvi} Inzerro, A., Oncologists, Hematologists Welcome CDC Clarification on Opioid Therapy for Chronic Pain, <https://www.ajmc.com/newsroom/oncologists-hematologists-welcome-cdc-clarification-on-opioid-therapy-for-chronic-pain>

^{xxvii} *Id.*

^{xxviii} FDA, Quantities of Opioid Analgesics Dispensed from Retail Pharmacies Approach Lowest Levels in 15 years, August 30, 2018, <https://www.fda.gov/about-fda/reports/quantities-opioid-analgesics-dispensed-retail-pharmacies-approach-lowest-levels-15-years>

^{xxix} Zhu, W., Chernew, M., Sherry, T., and Maestas, M, Initial Opioid Prescriptions Among US Insured Patients, 2012-17, N Engl J Med (2019), <https://www.nejm.org/doi/full/10.1056/NEJMsa1807069>

^{xxx} National Pain Strategy Overview, Interagency Pain Research Coordinating Committee, May 11, 2017, <https://www.iprcc.nih.gov/National-Pain-Strategy/Overview>