National Council on Independent Living

Statement of Principles - Chronic Pain / Opioids

July, 2018

People with chronic pain and other disabilities have been largely left out of the national conversation on opioids. The National Council on Independent Living (NCIL) believes that any discussion about opioid use and addiction must include the perspectives of people with chronic pain and other disabilities, including people with substance use-related disabilities. Similarly, all related legislative proposals must address the needs of these groups. Any approach to reduce opioid use must be balanced with the needs of people with chronic pain for whom opioid medications may be medically necessary.

More than 100 million Americans live with some form of chronic pain (Footnote 1). Nearly 40 million Americans report severe levels of pain (Footnote 2) and more than 25 million live with persistent, daily pain (Footnote 3). Chronic pain is a large umbrella category that varies from episodic to intractable and from mild to severe and covers a range of conditions. Although for some people with chronic pain non-opioid treatment might be effective, there are others for whom opioids are medically necessary.

As a result of recent efforts to reduce opioid prescribing, many people with chronic pain are being faced with forced opioid tapering or discontinuation. This has resulted in people with previously well-managed chronic pain facing agonizing pain levels and intense withdrawal symptoms. People who have experienced sudden dose tapering or discontinuation have reported increased suicidality, and a high number of suicide attempts and completion have been reported Footnote 4) by news outlets tracking the impact of forced tapering and discontinuation on people with chronic pain.

Approximately two and a half million Americans have substance use disorders related to opioids, both illicit and prescription (Footnote 5). National studies on drug abuse have found that the majority (over 75%) of people who report misuse of prescription opioids did not receive them in a treatment setting Footnote 6). According to CDC-cited research, between 0.7 and 8% of people with chronic pain who receive opioids may go on to develop an opioid use disorder (Footnote 7).

NCIL supports the following principles with regards to legislation and other proposals aimed at reducing opioid use and addiction:

- Legislation and proposals must not include arbitrary or blanket limits on prescribing amounts or dosages that would override individual, medically necessary treatment as determined by an individual and their doctor(s).

- Legislation and proposals must not institute unnecessarily burdensome requirements on individuals for access to treatment with opioid medications. This includes but is not limited to unreasonably frequent doctor visit or script requirements (Footnote 8) and ‘opioid tax’ proposals that do not include appropriate protections to prevent individuals who use opioid medications from increased costs associated with the tax.

- Legislation and proposals must not jeopardize the licenses of doctors practicing appropriate pain management with opioid medications. They also must not support pharmacies in refusing to fill legal, medically necessary (as determined by a medical doctor) prescriptions for opioid medications.

- Legislation and proposals must address the needs and specific barriers faced by frequently under-treated groups, including people with multiple chronic conditions, people with co-occurring chronic pain and mental health disabilities, people with multiple marginalized identities, people who are long-term and/or high-dose users, and people with rare diseases or disabilities.

- Legislation and proposals must not include new funding for forced or involuntary institutionalization or other forced or involuntary treatments. This includes forced tapering of people who are being treated effectively with opioid medications.

- Any treatment program for people with substance use disorders must:

    - Ensure that all program components are accessible to people with a variety of disabilities and access needs;
    - Provide a wide range of treatment options (not just one treatment method, such as medication-assisted therapy); and
    - Address the needs of people with substance use disorders who also need medical treatment for chronic pain.

In addition, NCIL encourages policy proposals that will provide additional treatments and alternatives for individuals with chronic pain. These include:

- Funding for research to better understand pain and develop new treatment modalities; both pharmacologic (including non-opioid and abuse-deterrent opioid) and non-pharmacologic, integrative treatments;

- Expanded access to palliative care;

- Expanded access to and coverage for effective, affordable, accessible non-opioid pain treatments, including but not limited to acupuncture, massage therapy, physical therapy, voluntary opioid tapering instruction and support, psychological treatments such as cognitive behavioral therapy, biofeedback, and meditation, medical marijuana, and other complementary and alternative treatments and therapies;

- Equitable access to treatment for chronic pain that is not reliant on geographical location, income level, or disability;

- Expanded educational requirements for medical professionals about treating pain – including training about chronicity – and addiction, both in medical school and through continuing education;

- Efforts to reduce the cost of medications, including specialty medications;

- Expanded access to the use of off-label prescribing of non-opioid medications for pain treatment; and

- Expanded access to long-term services and supports (LTSS) by requiring coverage by all providers.

Footnotes:

1. Institute of Medicine. (2011). *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research.* Washington, DC: The National Academies Press.
2. Nahain, R. L. (2015). Estimates of Pain Prevalence and Severity in Adults. *Journal of Pain 16*(8).
3. Ibid.
4. Kline, T. (2018). #OpioidCrisis Pain Related SUICIDES associated with forced tapers. *Medium*.
5. Volkow, N.D. (2014). America's Addiction to Opioids: Heroin and Prescription Drug Abuse.
6. U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration. (2014). *National Survey on Drug Use and Health.*
7. Edlund M. J., Martin B. C., Russo J. E., DeVries A., Braden J. B., & Sullivan M. D. (2014). The role of opioid prescription in incident opioid abuse and dependence among individuals with chronic noncancer pain: the role of opioid prescription. *Clinical Journal of Pain, 30,* 557–64.
8. Requiring unnecessarily frequent doctor visits can be both physically and financially burdensome for people with chronic pain due to a variety of factors including the cost of frequent co-pays, limited time off allowed by employers, barriers to accessible and affordable transportation, limited mobility due to pain or physical barriers, and others.