



Summary of Responses from a Request for Information: People with Disabilities and Opioid Use Disorder

About NIDILRR

The National Institute on Disability, Independent Living, and Rehabilitation Research's (NIDILRR) mission is to generate new knowledge and to promote its effective use to improve the abilities of individuals with disabilities to perform activities of their choice in the community, and to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.

As the federal government's primary disability research agency, NIDILRR achieves this mission by:

- providing for research, demonstration, training, technical assistance and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- promoting the transfer of, use and adoption of rehabilitation technology for individuals with disabilities in a timely manner; and
- ensuring the widespread distribution, in usable formats, of practical scientific and technological information.

NIDILRR grantees address a wide range of disabilities across populations of all ages in their research and development projects and knowledge translation activities.

Disclaimer

All statements in this publication, including its findings and conclusions, are solely those of the author and do not necessarily represent the views of the NIDILRR, ACL, or DHHS. Questions or comments may be sent using the below information.

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Executive Summary

The Request for Information (RFI)—People with Disabilities and Opioid Use Disorder, yielded comments from 50 respondents, including consumers, community and national organizations, research teams, and federal partners. Key findings from the RFI have been helpful to NIDILRR as it considers the development of new funding opportunities related to the opioid crisis. These responses have provided NIDILRR with information about what is known and what are the most pressing research questions for the disability and rehabilitation research fields. A common thread among respondents was that there are many important unanswered research questions at the nexus of chronic pain, opioid misuse, and people with disabilities.

This summary report provides a brief overview of the findings from the RFI responses and is organized as follows:

- **RFI Respondents:** includes overview of all RFI respondents
- **Key Themes from Respondents:** describes themes, including new knowledge about the prevalence of opioid use disorder among people with disabilities and the success of treatment strategies
- **Next Steps:** describes potential future funding efforts

Key takeaways from the RFI responses are as follows:

- New evidence suggests that people with disabilities are more likely than the general population to misuse opioids and develop an opioid use disorder but may be less likely to receive treatment than those without disabilities.
- Approximately half of the RFI respondents commented on barriers to treatment for opioid use disorder among people with disabilities, including physical accessibility of treatment centers, limited insurance coverage, and policies that withheld opioid prescriptions without first offering pain management alternatives.
- People with disabilities who experience a serious traumatic injury (e.g., spinal cord injury or traumatic brain injury) may be at greater risk of opioid misuse and unintentional death due to opioid poisoning.

Limitations of this assessment are that it draws mostly from the sample of voluntary respondents. For more details, please see the original RFI.

Introduction

Defined by the DSM-5, an opioid use disorder is a problematic pattern of opioid use leading to clinically significant impairment or distress, as manifested by clinically meaningful risk factors occurring within a 12-month period.¹ Opioid use disorder has been identified as an epidemic problem in the general population of the United States, requiring extensive interventions in policy and practice (Laxmaiah, 2012; Jette, 2018). However, little is known about the prevalence of this disorder among people with disabilities, and whether they experience disparities in accessing necessary treatment.

Following the release of an ACL issue brief on [The Opioid Public Health Emergency and Older Adults](#), NIDILRR became interested in the paucity of research focusing on people with long-term disabilities and their likelihood of developing an opioid use disorder. Although an extensive literature documents that chronic pain is more prevalent and under-treated among people with disabilities compared to people without disabilities (Ehde et al., 2003, Kennedy et al., 2014; Nampiaparamphil, 2008), the question remains as to whether people with disabilities seek and gain access to treatment when needed. It follows that they may also be underserved for treatment of pain, a factor that can lead to abuse of prescribed opioids or use of illegal opioids (Baker, 2017).

In January 2018, NIDILRR issued a Request for Information (RFI) on [People with Disabilities and Opioid Use Disorders](#) in an effort to address gaps in knowledge, mentioned above. This RFI invited stakeholders from the broad disability and rehabilitation communities to provide input about the prevalence of opioid use disorder among people with disabilities and about whether existing treatment strategies were accessible and adequate.

This document summarizes the input received from respondents to NIDILRR's [RFI](#). Input provided will help inform NIDILRR's future relevant funding opportunities.

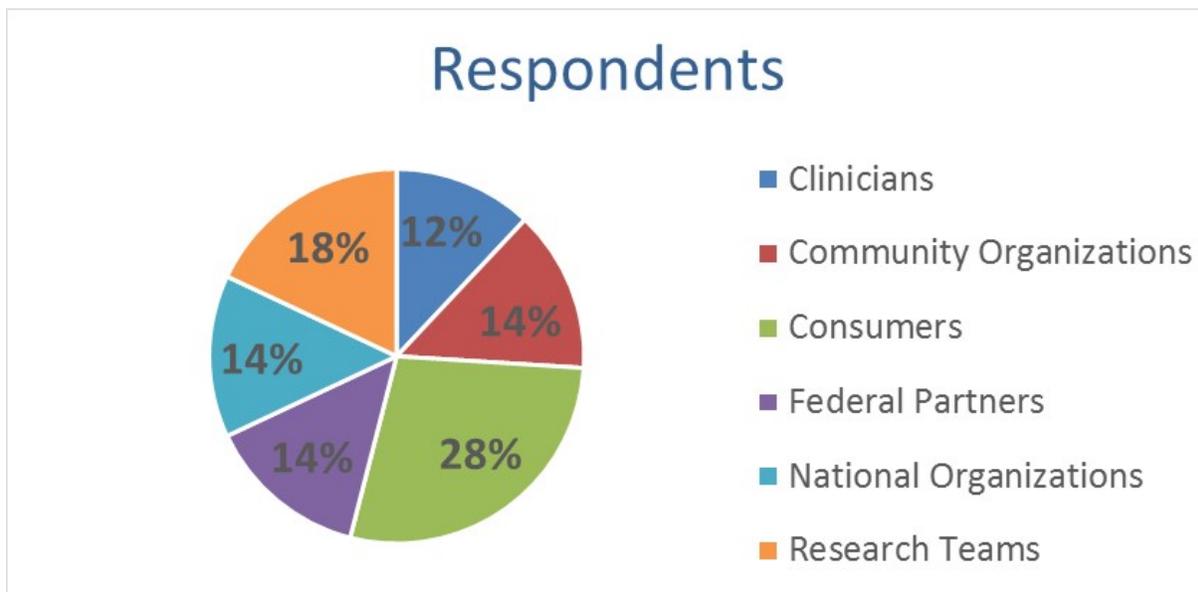
¹ For full definition, see [DSM 5 Definition of Opioid Use Disorder](#)

RFI Respondents

NIDILRR would like to thank the 50 respondents who provided information relevant to the RFI. Unless respondents gave permission to make their role in this report public, information about respondents has been de-identified throughout this summary. We publicly acknowledge the assistance of the following responding National and Community Organizations:

- Access Living Chicago
- Alliance for Treatment of Intractable Pain
- American Association of Nurse Practitioners
- American Physical Therapy Association
- American Psychological Association Division 22 Rehabilitation Psychology
- Colorado Cross Disability Coalition
- Michigan Opioid Prescribing Engagement Network
- National Council on Independent Living

The respondents were diverse geographically and by disability type. They represented 24 states and the District of Columbia, and, as noted above, included several national organizations. While many respondents could be included in more than one group (e.g., a clinician who was also a consumer with a disability), 12% were clinicians, 14% were community organizations, 28% were consumers, 14% were federal partners, 14% were national organizations, and 18% were research teams.



Most respondents focused on people with disabilities in general, but 25% focused exclusively on a subgroup such as people with physical, behavioral/psychiatric, intellectual/developmental, sensory, or cognitive disabilities, as well as people with disabilities from racial/ethnic minority groups, and Medicaid beneficiaries.

Key Themes from Respondents

New evidence suggests that people with disabilities are more likely than the general population to misuse opioids and develop an opioid use disorder but may be less likely to receive treatment than those without disabilities. Respondents submitted three studies that draw on two nationally representative data sources, the National Survey of Drug Use and Health and administrative data on beneficiaries who qualify for Medicaid on the basis of their disability.

Two studies using the [National Survey of Drug Use and Health](#) found that people with disabilities were more likely to misuse prescription pain medicine or use heroin than those without disabilities (Kennedy et al., 2018, Lauer et al., 2018). People with disabilities were at relatively high risk of opioid misuse or heroin use, due in part to the high prevalence of persistent pain and need for prescription drug relief.

A research team at IBM Watson Health, using [Truven Health MarketScan® Medicaid Databases](#), found that not only do Medicaid beneficiaries with disabilities have a significantly higher likelihood of opioid use disorder than those without disabilities (6.6% versus 4.2%), but also that beneficiaries with disabilities with a diagnosed opioid use disorder were significantly less likely to have a prescription for an approved treatment medication for opioid misuse (e.g., Medication Assisted Treatment; SAMHSA, 2018) than people without disabilities (11% versus 32%). That is, as a group, people with disabilities have a greater likelihood of having an opioid use disorder, and yet they are much less likely to receive treatment for it. This suggests that people with disabilities may face greater barriers to opioid use disorder treatment than those without disabilities. All three of the above studies point to the importance of research to assess barriers to treatment for an opioid use disorder among people with disabilities.

Approximately half of the RFI respondents commented on barriers to treatment for opioid use disorder treatment among people with disabilities, including physical accessibility of treatment centers, limited insurance coverage, and policies that withheld opioid prescription without first offering pain management alternatives. Physical accessibility of substance abuse treatment centers was the concern reported most by consumers; specifically, for respondents in rural communities with only one treatment site, these sites were often not accessible to wheelchair users. National organizations cited policy changes (e.g., caps on opioid prescriptions) as the greatest barrier to treatment. These policy changes would limit access to opioids and would cut off consumers “cold turkey” with no alternative pain management strategies offered. One especially concerning study on policy changes by the Drug Enforcement Administration found that 37.7% of consumers with fibromyalgia affected by changes to opioid access considered suicide (Kornblau, 2015; Kornblau et al., 2017; Chambers et al, 2015; Gleason et al., 2014). Respondents from community organizations reported insurance coverage,

including limited choices in local behavioral health offerings, as the most important barrier to opioid treatment.

Several respondents reported that people with disabilities who developed opioid use disorder are not able to access treatment for misuse of the drug. Respondents from the Cross Colorado Disability Coalition (CCDC) reported that Medicaid does not cover inpatient treatment and there are few detoxification facilities. Access to mental health services is limited and generally, people with opioid use disorders and co-occurring disabilities are turned away—even when Medicaid had prepaid through a managed care plan. Inpatient psychiatric facilities would not accept people with physical disabilities who have care needs such as personal assistance with bathing, dressing, and transferring. Moreover, the behavioral health system denied behavioral health services to people with a brain injury or intellectual disability, stating that the real problem is not opioid use disorder, but the other disability. According to the CCDC, even the crisis centers in Colorado offering short-term respite for people in crisis will not accommodate people with disabilities who had opioid use disorder.

Several national organizations asserted that any approach to the opioid crisis must balance the goal of decreasing opioid use disorder with the need for people with chronic pain to access adequate pain management. Consumer organizations reported that people with disabilities who use opioids responsibly as a way to control chronic and intractable pain are being treated as drug addicts. Many people are no longer able to hold down full or part-time employment, engage in volunteer work, or carry out other family responsibilities because pain is not appropriately managed. Additionally, when pain is not managed for people with disabilities, other problems emerge such as unexplained excessive blood pressure fluctuations, heart palpitations or racing, and falls due to extreme spasticity. These, in turn, increase emergency room visits and decrease function and quality of life.

People with disabilities who have experienced a serious traumatic injury may be at greater risk of opioid misuse and unintentional death due to opioid poisoning. Traumatic injuries, such as traumatic brain injury and spinal cord injury, often result in long-term disability, and have multiple secondary health conditions frequently treated with opioids. Three research teams submitted comments on these populations.

Spinal cord injury: New data indicate that opioid misuse is more prevalent among people with spinal cord injury than the general population (Hand, et al., 2018). Current research has identified a link between the frequency of prescription medication used to treat pain, sleep, and depression with adverse health outcomes (Clark et al., 2017; Krause et al., 2015). Recent research found that the use of pain medications is associated with greater risk of mortality (Krause et al., 2017), and that increases in frequency of pain medication use was associated with a greater risk of all-cause mortality (Cao et al., 2017). A new study (Krause et al., 2018) of people with spinal cord injury draws a definitive link between frequency of prescription medication use, sensation seeking, and binge drinking with unintentional death due to drug poisoning and overdose. A significant portion of these preventable deaths are directly related to opioid use.

Traumatic brain injury: Two research teams reported that people with traumatic brain injury are at a significantly greater risk for opioid misuse and overdose. Traumatic brain injury often results in headaches and orthopedic injuries for which they are prescribed opioids. In addition, traumatic brain injury also frequently results in impairment of cognitive functions such as memory, which may result in people forgetting that they have taken their pain medication, and therefore taking it again. It also frequently results in impaired judgement and impulsivity, which may also lead to overuse of pain medication. The aggregate consequences of the cognitive and behavioral impairments following moderate to severe traumatic brain injury typically results in difficulties with community re-entry, family adjustment and stability, and return-to-work resulting in mood disorders, for which they may self-medicate with opioids. Further, between 70-80% of patients with traumatic brain injuries are discharged with a prescription for an opioid (Hammond et al., 2015). Analyses of 14,398 subjects in the NIDILRR Traumatic Brain Injury Model Systems database² revealed that people with traumatic brain injury were 11 times more likely to die of overdose than the non-brain injured population (Hammond et al., 2018). At the present time, there are no opioid prescribing guidelines for people with traumatic brain injury.

Next Steps

NIDILRR recognizes the urgency of further research based on RFI responses and is engaging in internal efforts to explore the potential for future funding opportunities to generate new knowledge and promote its effective use to address the opioid crisis and its impact on people with disabilities. Several possible future funding areas include:

- Systematic reviews of existing literature on opioid use disorder and people with disabilities.
- Prevalence estimates of opioid misuse and treatment patterns for people with disabilities using secondary data sources.
- Individual and environmental factors associated with increased risk for opioid use disorder for people with disabilities.
- Individual and environmental factors associated with improved access to treatment for opioid use disorder for people with disabilities.
- Interventions that contribute to improved outcomes for people with disabilities diagnosed with an opioid use disorder. Interventions include any strategy, practice, program, policy, or tool that, when implemented as intended, contributes to improvements in outcomes for people with disabilities.
- Effects of government policies and programs on health care access and on treatment outcomes for people with disabilities who have an opioid use disorder.

² For details, see [Traumatic Brain Injury Model Systems Website](#)

We invite the disability and rehabilitation communities to continue to provide critical information to shape NIDILRR's funding priorities. Please send additional responses to Sarah Ruiz at sarah.ruiz@acl.hhs.gov.

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