COLORADO CROSS-DISABILITY COALITION

SUD Treatment Barriers

For people with disabilities

Introductions

- **Julie Reiskin**, Executive Director Colorado Cross-Disability Coalition

- **Kate Nicholson**, National Council on Independent Living; former career civil rights and ADA attorney & manager at Department of Justice

ADA: The Basics

- People with SUD in treatment are covered under the ADA as people with disabilities.
- People with other disabilities have a right to receive the same level treatment as others.
- What Treatment Providers must do:
  - Effective Communication including ASL
  - Provide or allow personal assistance
  - Modification of policies, practices or procedures unless it causes a fundamental alteration

Disability Cultural Competency

‘one size fits all’ fits no-one

Barriers to Care

- People with disabilities are facing extreme barriers in receiving treatment in the overdose crisis.

- Some of this has to do with the demonization of opioids & conflating addiction/dependence or treating all use as misuse.

Addiction/Dependence

- Addiction is “a chronic, relapsing disorder characterized by compulsive drug seeking and use despite adverse consequences." This differs from "physiological dependence," an inevitable outcome that results from the continued use of many medications— not just opioids. Physical dependence lacks behavioral elements that are the hallmark of addiction, or substance use disorder. (source NIDA)

Barriers (cont.)

- People who use opioids legitimately as treatment for pain or an opioid use disorder are protected by the ADA.
- But both groups face barriers in receiving medical treatment, **not just SUD treatment**.

Pain Patients

A recent NEJM study found 40% of primary care doctors refuse to treat pain patients who use prescription opioids.

Patients with OUD

DOJ recently settled with a practice that refused to treat someone with an OUD who used buprenorphine (SELMA).

Barriers (cont 2.)

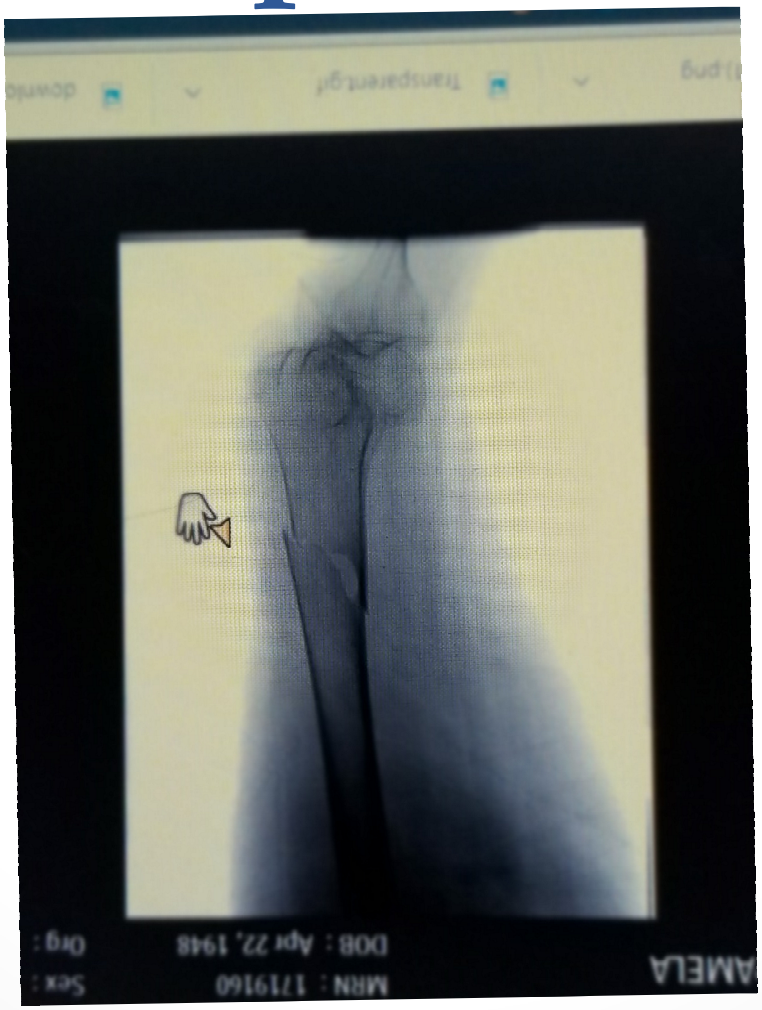
- Lack of disability cultural competency in SUD providers especially for people with both SUD and chronic medical condition
- Lack of consistent ADA enforcement for all providers that receive state funds (crisis, SUD, Medicaid)
- No well known source for advocacy when people are turned away

Case Study

- 70 year-old low-income woman on Medicaid
- History of mental illness
- History of stroke & chart says stroke occurred due to something related to drugs
- Several other medical conditions
- Visited 4 emergency rooms in past two weeks complaining of pain

Should she be referred for SUD treatment?

This is the reason for the pain



And by the way

- Has been in treatment for mental illness for decades
- Stroke was caused due to improperly packaged cold medications
- She took two

decongestants working

at her law-office

30 years ago

Barriers to treatment

- Many people with disabilities live with complex or multiple conditions
- Many people with disabilities have chronic intractable pain as part of their disability
- The lack of access to and coverage of alternative treatments for pain is a major barrier to care and driver of opioid reliance

Barriers to Treatment/Opioid Crisis

PostEverything • Perspective

The problems with one-size-fits-all laws on opioid prescriptions

Politicians keep proposing overly rigid rules that harm people in pain.

- Pill limit laws and policies negatively impact access to medication.
- People with disabilities who have pain, substances use disorder or are in recovery and using opioids are being abandoned in care, or there is an outright refusal to treat – both violations of medical ethics and the ADA

Barriers in treatment

- Abstinence only policies
  - This is a problem across the spectrum of SUD/disability; it effects professionals with SUD as well

- For example, this piece in NEJM about the irony that physicians have pushed for evidence-based treatment and buprenorphine and yet many physician health programs often mandate abstinence-based models of treatment for OUD

Barriers in treatment - Tapering

- Tapering policies – patients are having their dosages involuntarily reduced or eliminated. Human Rights Watch issued a report finding that that **clinicians were force tapering out of fear of liability even against their best medical judgment.**

- Kaiser Permanente Colorado study found that simply destabilizing dosage resulted in a **3-fold increased risk of opioid overdose** even after controlling for dose.

- Vermont study found most at (120 MME for > 90 days). **The median length of time to discontinuation was one day and 49% had an opioid-related hospitalization or emergency department visit.**

- **National Academy of Medicine, Best Practice Standards**

Poor outcomes

PATIENTS WHO ARE ACUTELY SUICIDAL

"I am a pain patient who can no longer get treatment for my pain caused by a spinal cord injury. I do not want to [end] my life. I want to live. I want to see and hold my grandson. If I cannot get help from someone, somewhere, I will not be here next week."

FAMILIES WHO HAVE LOST LOVED ONES

"My brother passed away. Over the last year, his doctors began to significantly cut down his pain medication. He was truly at the end of his rope."

PATIENTS WHOSE LIVES ARE SEVERELY DISRUPTED

"I was independent - now I have to get my kids to help me because I am bedridden …so I get disability now and lost my house." or "The tears, grieving, financial loss cannot be described [with] my husband bedridden in immense pain. I am so tired now and we are financially devastated."

Barriers in Treatment

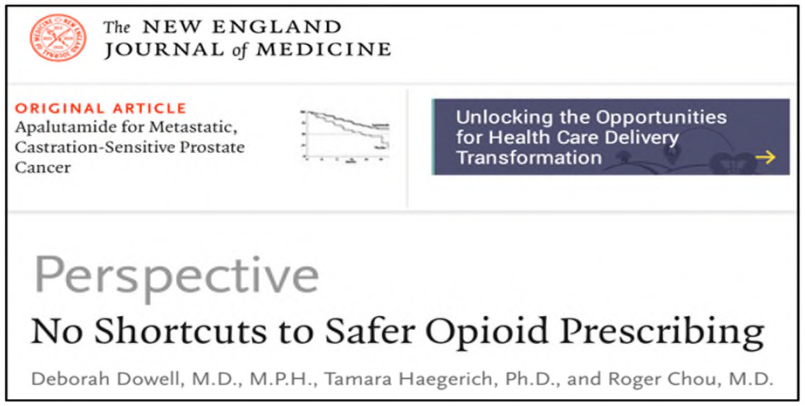
- Urine Drug Testing (sometimes false positives)
- Flagging of patients and non-transparent use of Medical information (Example: story of outgoing President of AMA (also: Narxcare/Apriss)).
- The appropriate response even to appropriately identified drug-seeking behavior is never dismissal from care.

2019 Formal Guidance – CDC –

Strict Application of 2016 Guideline May Harm Patients

NEJM: STRICT OR HARD LIMITS, OVERREACH TO UNINTENDED POPULATIONS

DIRECTOR REDFIELD: THE RELEVANT CALCULUS FOR LTOT PATIENTS IS **BENEFIT VS. RISK, NOT A SET MME.**


The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE
Apalutamide for Metastatic, Castration-Sensitive Prostate Cancer

Unlocking the Opportunities for Health Care Delivery Transformation →

Perspective

No Shortcuts to Safer Opioid Prescribing

Deborah Dowell, M.D., M.P.H., Tamara Haegerich, Ph.D., and Roger Chou, M.D.

"The Guideline does not endorse mandated or abrupt dose reduction or discontinuation, as these actions can result in patient harm. The guideline includes recommendations for clinicians to work with patients to taper reduce dosage **only** when patient harm outweighs patient benefits of opioid therapy. The recommendation on high-dose prescribing focuses on initiation. The Guideline offers **different** recommendations for patients already on opioid dosages greater than 90 morphine milligrams equivalent per day."

Photo of NEJM article and Director Redfield letter

FDA – Warning/Label Change on Tapering

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

[4-9-2019] The U.S. Food and Drug Administration (FDA) has received reports of serious harm in patients who are physically dependent on opioid pain medicines suddenly having these medicines discontinued or the dose rapidly decreased. These include serious withdrawal symptoms, uncontrolled pain, psychological distress, and suicide.

Forced Tapering or Discontinuation

- Leads to illicit use
- Leads to increased alcohol use
- Leads to using a dispensary as a medical provider (often mixing with OTC, alcohol)
- Leads to suicide attempts
- Leads to increased ER visits

Stigma

Problems

- Multiple overlapping stigmas
- Stigma about disability
- Stigma about pain
- Stigma associated with use disorders
- These are bootstrapping on each other
- Stigma from laws/policies: systemic barriers to care and stigma arise from laws and policies

Solutions

- Assure state oversight is not making things worse
  - Protect providers that treat complex patients especially those who responsibly prescribe Opioids and MAT
- Disability Cultural Competency training for SUD providers and medical providers
- Check with disability advocates when advancing any policies related to OUD to assure no inadvertent harm
- Require Medicaid and state regulated insurance to have exceptions to MME limits

Further questions

kate@katemnicholson.com
jreiskin@ccdconline.org