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Perspectives of adults with disabilities and opioid misuse: Qualitative findings illuminating experiences with stigma and substance use treatment

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ABSTRACT

Background: Opioid misuse is a significant public health problem in the United States; however, there is a gap in knowledge regarding the experiences of individuals who have experienced both opioid misuse/opioid use disorder (OUD) and another disability. This gap in knowledge is particularly problematic because people with disabilities are more likely to have co-occurring serious mental illness, experience chronic pain, and be socially isolated, which are all independent risk factors for any substance use disorder (SUD).

Objective: The purpose of this study was to illuminate the perspectives of individuals who have both opioid misuse/OUD and another disability, focusing on their experiences accessing and engaging in SUD treatment.

Methods: We recruited adults who had lived experience with both disability and an “opioid use problem.” We conducted 17 individual interviews and facilitated two focus groups with 11 participants. The interview protocol included items related to individuals’ experiences with OUD/SUD treatment as well as stigma.

Results: Respondents encountered many barriers to receiving SUD treatment related to their disability. People with disabilities experienced added layers of stigma and other systemic barriers (e.g., lack of accommodations) that complicated treatment quality and access. This was further compounded by intersecting identities (e.g., female gender, race, homelessness).

Conclusion: SUD treatment providers should be trained to understand and adopt accommodations critical to the unique needs of individuals with disabilities, with cultural responsiveness, to encourage successful SUD treatment and recovery.

Opioid misuse remains a public health concern in the United States.[1,2] Though a breadth of research has been conducted pertaining to opioid misuse, much less is known about how it has impacted people with disabilities. This is particularly concerning because people with disabilities are more likely to have co-occurring serious mental illness,[3] experience chronic pain,[4] and be socially isolated,[5] all of which are independent risk factors for substance use disorders (SUD).[6] A study conducted with national survey data from 2015 to 2016 found that adults with disabilities were significantly more likely than adults without disabilities to experience past-year prescription opioid use (52.3% versus 32.8%, respectively), misuse (4.4% versus 3.4%), and use disorders (OUD;

Abbreviations: SUD, substance use disorder; OUD, opioid use disorder; CDT, critical disability theory; ADA, Americans with Disabilities Act.

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1.5% versus 0.5%).[7] Further, other recent studies discovered that Medicare patients admitted to hospitals for opioid poisonings and overdose deaths were more likely to be persons with disabilities.[8,9]

There is a gap in knowledge regarding the experiences of individuals who have both opioid misuse/OUD and a disability, as most existing research is focused on substance use disorders (SUD) more broadly. Some studies, however, have found that people with mild/borderline intellectual disabilities are less likely to initiate and engage in SUD treatment and more likely to leave treatment early.[6,10] The nature of a person's disability may make it more challenging to travel to a SUD treatment center.[11,12] SUD treatment providers may not have the expertise or capacity to provide individualized treatment plans to address the needs of persons with disabilities.[10,12] Despite the Americans with Disabilities Act (ADA) mandating accessibility, studies indicate many treatment settings are not fully accessible for people with disabilities.[10,13,14] People with disabilities also experience stigma, stereotypes, paternalism, and other systematic barriers that complicate SUD treatment quality and access.[12] This includes the false narrative that people with disabilities do not have SUD, that they are not able to maintain recovery, or that they will be "too difficult" to serve.[15] For dually-disabled individuals with SUD and other type of disability, stigma will be compounded by the stigma people with SUD often encounter.[16]

Theoretical framework

Critical disability theory (CDT) builds upon Crenshaw's theory of intersectionality and how disability interacts with multiple identities.[17] Crenshaw describes intersectionality as not simply a race, class, gender, or other identity problem in isolation, but "where power comes and collides."[18] Each identity layer can act as additive or multiplicative in terms of health and social outcomes.[19] CDT recognizes that people with disabilities do not share equal levels of exclusion/stigma and that barriers are compounded by various identities, including having an OUD or other SUD.[20]

These theories inform our hypothesis that individuals who are dually-disabled will face unique types of barriers and stigma, which will be further influenced by their other identities.

"Intersectional stigma" is another key part of our framework.[19] Stigmatization happens when society devalues different identities or characteristics, leading to decreased power and increased exclusion/discrimination.[19] Stigma also creates barriers to help-seeking behaviors and accessing services, and may lead to broad discrimination.[21] Our study population is at least dually-disabled, therefore their experiences are informed by this intersection in addition to other identities they have.[19,22] Understanding their stories is pivotal to inform better treatment for OUD/SUD among this population.

Aims

The purpose of this study was to illuminate the experiences of individuals with both a disability and opioid misuse/OUD, focusing on their experiences initiating and engaging in OUD/SUD treatment. Using a CDT lens, we investigated whether individuals' unique identities, or experiences with stigma and barriers, influenced their OUD/SUD treatment experiences or their addiction. To achieve these aims, we conducted in-depth interviews and focus groups among individuals with both disabilities and opioid misuse/OUD.

Methods

We utilized a community engagement framework[23] for the study design, and partnered with the Disability Policy Consortium in co-designing the interview protocol, screening tools, coding, conducting the interviews/focus groups, and analysis. We recruited adults who self-identified as having lived experience with both a disability and an "opioid use problem," not requiring OUD or specifying opioid use/misuse as prescribed versus illicit, for inclusion in an effort to encourage participation. During the screening, we gathered information on gender, disability type, and race/ethnicity of respondents. Our original goal was to conduct 3 focus groups in Massachusetts. We began recruitment in the summer of 2019 using a multifaceted recruitment strategy (e.g., flyers, targeted emails, social media, advertisements), yet after several months, we experienced difficulty recruiting, despite our community engagement approach. Therefore, we modified our approach to recruit participants for one-on-one interviews. We conducted 17 individual interviews between October 2019 and August 2020: 6 in person, 5 by phone, and 6 by videoconferencing after the COVID-19 shutdown in March 2020. We worked with leadership at homeless shelters to recruit 2 focus groups, which were held in 2020 prior to the COVID-19 shutdown, with 5 and 6 participants.

The interview protocol was the same for interviews and focus groups, including items related to individuals' experiences with OUD/SUD treatment (see Table 1 for protocol details). Despite recruiting based on opioid use problems, and an interview guide focused mostly on OUD, many respondents talked about SUD more broadly. Where the response was specific to OUD, that is noted; otherwise, we refer to SUD. In general, we refer to SUD treatment as inclusive of addressing OUD. Respondents received a $50 gift-card as an honorarium.

This study was reviewed and approved by the Brandeis University Institutional Review Board.

Analysis

Interview and focus group recordings were professionally transcribed and uploaded into Dedoose.[24] We utilized thematic analysis to approach our theme development.[25] Initial codes were deductively developed by the team, mapping to themes from the protocol and a priori code ideas relating to CDT. A few codes emerged during this process (e.g., peer support). As training, all 3 study coders independently coded the first interview then met to discuss our codes. When divergent codes were used, we came to a consensus about the most appropriate codes to develop a shared understanding of the code definitions. We then had two coders for each transcript. The primary coder coded the transcript first, then the secondary coder reviewed the transcript in detail and generated a memo if there was a request to modify or delete codes. These differences were discussed and resolved for each transcript. Once coding was completed, research team members generated memos by theme.

Results

Respondents were, on average, 49 years old (range 30–66 years), and the majority were female (53.6%). Mental disabilities were most commonly reported (46.4%), followed by physical and mental disability (28.6%), and physical only (25.0%). Almost half reported being White/non-Hispanic (46.4%), with 3 identifying as African American or Black/non-Hispanic (10.7%), 2 identifying as 2+ races (7.1%), and 1 identifying as Hispanic. Nine individuals (32.1%) did not report a race/ethnicity.

Table 1
Interview/focus group protocol: Questions and probes.

Question Domain	Example Probes
Needs in terms of opioid problems/ opioid misuse/opioid use disorders, their treatment, or recovery supports	When I say the words “opioid problem,” “opioid misuse,” “opioid disorder,” what do they mean to you?
Pathway to OUD	Can you share a little bit about your history with opioid use? What kind of opioid did you first have problems with? [probe: prescription, heroin, fentanyl] • [If prescription] How was it prescribed to you? Did you request an opioid from your doctor, or was it provided to you? • [If prescription] Can you say a little bit about what type of pain you were experiencing when you were first prescribed an opioid? ○ Physical pain ○ Reduce stiffness ○ Reduce stress, anxiety, or another mental health reason
Knowledge about OUD treatment including medications	We're going to talk a little bit about treatment and your experience of treatment, but first it would be helpful to know what you have heard about treatment for OUD? • Have you heard about buprenorphine, methadone or Vivitrol? What do you think about them? • Can you talk about how you first heard about OUD treatment? A friend, family member, or provider or some other way?
Engagement in treatment	It would be helpful to know if you would be willing to share whether or not you have been in treatment, are in treatment now, or have completed treatment. • Could you say more about why you have or have not entered treatment?
Barriers that exist or might arise in terms of getting into, participating in, or finishing treatment	What kind of challenges have you had in getting treatment? What kind of personal barriers do you face in terms of stigma, or fear of loss of disability or health benefits, or fear of the unknown? • Medical complexities, mental health issues, physical or communication limitations, pain • How difficult or easy was it for you to get treatment when you found out about it? • Finding an accessible treatment location? • Pain management? • Permission to take other medications prescribed by a doctor? • Finding PCAs (personal care assistants)? • Cultural challenges race, language, disability
Solutions you have discovered to overcome these barriers	What has worked for you in obtaining treatment? If you have not been in treatment but think it might be helpful, what types of supports do you think would assist you to get treatment? Probe: social supports, supports from service or provider organizations Can you tell us a little bit about who the supports are in your life that help you, related to treatment?
Successes, questions that remain unknown	What recommendations would you make about treatment to other people with disabilities who misuse opioids?

Stigma

Stigma was a concept interwoven in most of the participants' interview responses, reporting experiences with stigma before, during, and after treatment. Several participants described feeling like they were treated like “less of a person” or “weak-minded” because of their OUD and co-occurring disability. Another person described stigma as the “hardest part about addiction.” Several respondents reported feeling pre-judged by people or that they had difficulty admitting they needed help with their OUD because they were “concerned about what other people think.” Respondents noted they feel “too much shame” to seek help. Another reported moving to another city to “leave behind” the stigma from their old community. Respondents said that the following would help to reduce stigma: increasing understanding that OUD is a disease, more openness with their stories about relapse and recovery, and more support for medication treatments.

Pathway to OUD

Though every person's pathway to OUD is unique, many respondents noted that their first exposure to opioids was by a prescription because of an accident or medical issue. For example, one respondent started taking prescription opioids after an ankle injury and eventually began wanting to take them “with the intention of getting high.” Multiple respondents mentioned medical providers prescribing opioids without much care, which facilitated their development of misuse. One respondent shared that they had back surgery and their “doctors turned on a never-ending faucet of opiates.”

Conversely, several respondents reported challenges receiving adequate pain management from clinicians. Chronic pain was a common experience, and many respondents were still struggling with how to live with ongoing pain. One respondent began misusing opioids because their doctor didn't take their chronic pain seriously, so they sought “pain relief elsewhere.” Another respondent in recovery reported crying “from the pain” they experience. Another respondent stressed that providers need to be aware of pain among patients with a history of addiction rather than just letting them be in pain.

Mental health and trauma were other common pathways to OUD. One respondent mentioned they were diagnosed with bipolar disorder and were prescribed opioids after multiple surgeries. This respondent “enjoyed” the feeling they had on the opioids and preferred them to antidepressants. After sharing this with their doctor, the clinician said, “Why don't we experiment?” After that, this respondent said, “a switch was flipped,” and they “felt like an addict brain had already taken over.” Other respondents mentioned how using substances helped ease feelings stemming from trauma or self-hate. One respondent said they were “a little boy who didn't like being in his own skin,” but as soon as they “put a substance into [their] body, that didn't bother [them] anymore.” Multiple respondents described having mental health issues before their substance use and that substances were one way to manage their mental health symptoms. Others described multigenerational SUD, observing substance use in their home or community as a contributing factor in their pathway to OUD.

Several respondents realized they had a problem with opioids when they began taking the medication more than prescribed, realizing they felt a “need for that feeling” the opioids provided, began “manipulating” their doctor to obtain more, or began purchasing them off the street. Many participants defined misuse of opioids as using “them incorrectly” or not “as prescribed” but that misuse has the potential of leading to OUD.

SUD treatment

Facilitators: All respondents had some personal experience with SUD treatment in relation to their opioid misuse or OUD. Several respondents talked about the difficulty of seeking treatment and the need for support because it is a “scary” thing to go through. Having a support system and “someone that really cared” was described as a facilitator to treatment. Another mentioned that they had to forgive themselves in order to be successful with treatment. Others talked about how being physically removed from their usual environment facilitated treatment, whether that was by staying with family or being incarcerated; it helped them feel “safe” and allowed them to focus on treatment. Having access to affordable, quality treatment was also a facilitator. A few respondents mentioned how the presence and severity of fentanyl in street drugs scared them and influenced their decision to seek treatment.

Many people reported that their anxiety, depression, and trauma were the core of why they used opioids and that it was critical that it was acknowledged and treated during SUD treatment. A few respondents discussed how having access to a variety of complementary and integrative health treatments was useful for them (e.g., swimming, peer support), in addition to diverse, trauma-informed care. Several others discussed how medication treatment (e.g., buprenorphine) has been a central part of their recovery, although some felt stigmatized for using medications to treat OUD. One respondent described how they were in a cycle of relapse and detox until they were prescribed methadone, then eventually buprenorphine, which has supported their recovery for ten years. Another reported that being prescribed buprenorphine and an anti-depressant has been key for their recovery.

Barriers: Respondents reported numerous challenges with treatment, including not having a sufficient number of programs accessible, a lack of specialized programs for people with dual-diagnoses and diverse populations, affordable/consistent transportation, lack of access to affordable quality care, and stigma/shame. One respondent reported waiting lists as a significant barrier. A respondent described how when people say they want help, they need help immediately and that “the window of opportunity is very small.” Respondents noted that their access to treatment was often limited by what they could afford; a few mentioned family members paying for treatment programs, while others relied on public and private insurance.

Some mentioned that having medical complexity (e.g., disability, asthma, mental health) could be a barrier, with one respondent describing treatment centers being hesitant to take them on because of their physical health problems. Another said they were not allowed to take their ADHD medication while in treatment, which they attributed to their relapse. One respondent said they were unable to get mental health medication in treatment, which they felt delayed their recovery. One respondent reported not mentioning their mental health diagnosis to SUD treatment providers because they were nervous the provider would “not look at you too kindly” because of “stigma.” Another reported they wanted more respectful treatment groups, saying they felt silenced if they made small mistakes or misspoke. Others mentioned being afraid that treatment would not work or that the length of the treatment episode would be too short. A few respondents described being afraid of seeking treatment, knowing that it was going to take “a lot of effort,” having a “fear of succeeding,” and that it may make them feel “worse.”

Accessibility: The need for a personal care attendant or other designated support staff was also a common issue, particularly among those with a physical disability. One respondent mentioned that they typically did not remove their jacket during sessions, even if too warm, because they do not want to ask for help or feel like a “burden.” Others noted that they felt uncomfortable asking for help and desired designated support staff. Transportation was another common accessibility concern. Participants mentioned that it was often difficult getting to treatment and they felt like they were “inconveniencing people” if they asked for help. Respondents reported that having a pre-paid transportation service was helpful (e.g., paratransit, Uber/Lyft).

Respondents suggested a more person-centered approach to working with people with disabilities. One respondent reported feeling “disadvantaged” and “left-out” in a treatment session when the provider mentioned the importance of physical activity and accessing the community as part of the recovery process but did not offer alternatives to modify these suggestions to meet the person's needs. Another respondent lamented that treatment providers are “just are not as good with people with disabilities.”

Peer support

Peer support, a mentoring and support service typically provided by people in recovery from SUD,[26] was consistently mentioned as an integral part of OUD recovery journeys. Several respondents talked about how peer support provides value by providing “non-judgmental” support, feeling comradery that they are “in the same boat,” learning from “each other's past experiences,” offering “solidarity,” helping “navigate” services/treatment, and someone to “listen” when needed. One noted that in a peer-led setting, you could hear what “everybody else's thinking, and you come to hear how alike you are.” Another respondent said it was particularly helpful to talk with peers with a disability about opioid misuse.

Other stigmatized identity experiences

Respondents highlighted experiences related to belonging to a stigmatized group (e.g., gender, race, LGBTQ+) as impacting their OUD or broader SUD recovery journey. One respondent who self-identified as a Black man discussed how he is hyper-vigilant in the community and in treatment settings. He reported that he's been in treatment programs where a small infraction led to discharge, while White individuals are allowed to remain even when making larger infractions. Another respondent mentioned the need for more minority-led recovery centers and counselors. This person mentioned the need for people to “pull up our own” and went on to say, “you can't look to someone who hates you … to truly help you.” Other respondents mentioned that they have not seen much change in cultural competence and feel like “the color of your skin will force you out of treatment.”

Another respondent who self-identified as being part of the LGBTQ + community said they have been in treatment settings that “aren't welcoming to the LGBTQ + community” and expressed the need for better ways to identify LGBTQ + friendly providers and centers such as “signage on the doors.” Female respondents noted a lack of services available to women with OUD and that “the system sets us up to fail.” Others noted that current programs for women are often targeted to specific sub-populations, such as pregnant women or women with children. Several described a desire for more women-specific treatment options; one woman noted that there is a “solidarity between women” and described how “it takes trust … that's why it's easier when you see other women succeeding.” Another respondent who self-identified as an African

American woman said she would “have felt a little bit more comfortable” in a treatment setting with other people who looked like her.

Impacts of OUD

One respondent mentioned that while they were actively misusing opioids, they hid from their family and children for months. Others mentioned being suicidal and described a period of “lost” time while they were in active use or losing relationships with their family or jobs. Many mentioned they felt like they had “burned so many bridges” that they had to “rebuild.” One respondent mentioned they have been chronically homeless since 2004 due to their OUD and traumatic brain injury.

Multiple respondents mentioned engaging in criminal behaviors to support their drug addiction. One described living with their dealer and “running a brothel” prior to seeking treatment. They also had their children removed by child services while they were in active use and in and out of jail. Several respondents mentioned that one of their first experiences with treatment was in prison, giving them access to therapists and treatment programs that they did not have access to before. Some mentioned how the opportunity to participate in drug treatment programs during their prison sentence was impactful because it “has structure … education” and helps people be around others who “want help and are willing to do the work.” Others mentioned cycling in and out of jail, indicating periods of sobriety, but being pulled back into substance use again.

Discussion

Opioid misuse/OUD remains a public health concern. To our knowledge, this is the first study to illuminate the voices of persons with both disability and opioid misuse/OUD to learn more about their experiences with treatment. The interviews and focus groups were extremely rich, and here we highlight the most prominent issues reported by the respondents, including their pathway to OUD, broader experiences with SUD, barriers and facilitators to treatment, stigma, and intersectional experiences.

Stigma has a profound impact on people with SUD. Stigma can impact the allocation of resources, clinician behaviors in screening and treatment, and willingness to attempt to seek treatment.[27] Among people with both a disability and SUD, this stigma is further compounded by other intersecting marginalized identities.[12] As noted by some respondents, discrimination creates “real disparities” in the treatment system in terms of opportunity and how clinicians interact with them.[28–30] This is a significant issue for people with multiple marginalized identities, echoed by respondents who identified as an intersectional minority. Lack of representation and trust remains a significant problem that needs to be addressed.

Many respondents reported that their pathway to opioid misuse/OUD was related to experiences with chronic pain and/or mental health conditions, which are known risk factors for prescription opioid misuse and more common among persons with disabilities.[31,32] Disability is a stigmatized trait, and many participants did not strongly identify with having a disability. Within our study population, many respondents reported many barriers to treatment. However, they often attributed the barriers to other factors, rather than suggesting that these challenges may be impacted by having a disability. Over half of the respondents in our study had a mental health disability, yet many did not use language to suggest that they identified as having a disability due to their mental health condition.

Access to equitable care that provides appropriate accommodation is a facilitator to treatment. Conversely, the absence of accommodations creates barriers for people with disabilities attempting to access SUD treatment. Several respondents described how not having accommodations in the treatment program made them feel “disadvantaged.” Further, without necessary supports to help them attend treatment services and to address self-care needs during treatment, respondents felt like a “burden” or that they were “inconveniencing” people.

Research has shown that insufficient clinician training on treating clients with disabilities, as well as a lack of physical accommodations, are key barriers for people with disabilities to accessing SUD treatment.[33] Our findings echo that and further suggest that trauma-informed, person-centered services that address/accommodate co-occurring needs are necessary. Although rates of SUD among people with disabilities are higher than in the general population, people with disabilities are less likely to enter SUD treatment and are more likely to be denied treatment.[7,34,35] Several respondents lamented that clinicians often do not know how to engage with people with disabilities and often do not address co-occurring issues during treatment. A recent study of physicians across the U.S. found that only 41% were very confident about providing high quality care to patients with disabilities.[36] These alarming trends may contribute to worse quality of care for people with disabilities seeking SUD treatment. Despite the ADA mandating accessibility and reasonable accommodation, providers may not understand how to provide accommodations to clients with disabilities and therefore provide lower quality, inequitable care.[14]

Peer support is a growing service-delivery model in the behavioral health field which has the potential to help people with disabilities and OUD, though there has not been much research to date investigating peer-support at the intersection of disability and OUD/SUD.[26,37] Many respondents described peer support services as a source of non-judgmental assistance while navigating the treatment system and appreciated the individualized support. The flexibility of peer support may be particularly helpful for people with disabilities, given that peers often interact with people seeking treatment more informally and as needed.[38,39] Having a peer that also has a disability could be especially impactful for this patient population, though it may be challenging to recruit peers with lived experience with both conditions.

Overall, participants noted there needs to be more work to destigmatize OUD/SUD and disability, so people are able to seek treatment when needed and receive quality, equitable care targeted for their needs. People with disabilities need access to various types of SUD treatment, including medication treatment, alternative modalities, and treatments that address co-occurring needs in a way that minimizes stigma. In spite of the evidence that medication treatments are effective for OUD in reducing deaths and relapse, stigma and misunderstanding about medication treatments remain common even in SUD treatment programs and have resulted in its underuse.[40] It remains unknown if persons with disabilities face greater challenges accessing medication treatments due to reduced power, stigma, lack of accommodation, or other barriers to accessing the treatment due to requirements for daily, in-person receipt outside of the home (i.e., methadone). More research is needed to understand these issues among people with disabilities. Greater emphasis is needed to develop peer supports as part of the person's care team, especially peers that also have a disability. There needs to be more person-centered care delivered that is accessible, including assistance with transportation, course content, physical accessibility, and provision of personal care attendants. Lastly, better representation of people with disabilities and OUD/SUD from diverse backgrounds is needed within the treatment and peer supports systems and to improve targeted programs for these populations.

Limitations

This study relied on purposeful sampling in one state and may not be generalizable to all populations of individuals with disabilities and OUD/SUD. Most respondents reported mental health and/or physical disabilities, and therefore our population may not reflect the experiences of people with other types of disabilities (e.g., intellectual disabilities). Additionally, since most interviews were conducted face-to-face, social desirability bias may have occurred if participants did not disclose certain experiences due to shame/stigma. Because some respondents were in SUD recovery, this may have introduced recall bias in terms of their substance use experiences. Lastly, even though all respondents reported having a disability when screened, some with mental health disabilities did not use language suggesting they identified as having a disability, which could have impacted how they described their experiences.

This study used a broad definition of having an "opioid problem" and could potentially be missing more nuance associated with illicit versus prescribed opioid misuse; this is an important avenue for future research. Our definitions of treatment were also broad, therefore more research specifically into the role of medication as a facilitator or limitation for people with disabilities would be helpful. The intersectional framework offers valuable guidance into how to approach the dually-disabled, and future research would benefit from this perspective.

Conclusion

Substance use disorders can have significant impacts on individuals and the people who love them. Respondents described encountering many barriers to seeking and receiving OUD/SUD treatment related to their disability. People with disabilities experience added layers of stigma, paternalism, and other systematic barriers that complicate treatment quality and access. This is further compounded with other intersecting identities. OUD/SUD treatment providers should be trained to understand and adopt accommodations critical to the unique needs of individuals with disabilities, to encourage successful treatment. Further research and policies are needed to develop, evaluate, and implement SUD treatment in a manner that supports persons with disabilities from diverse backgrounds. There are no simple one-size-fits-all solutions to address the multifaceted needs of this population. Treatment of people with OUD, and those with disabilities in particular, requires person-centered care plans and opportunities that meet their particular needs.

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Disclaimer

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Conflicts of interest

No declared conflict of interest.

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