

Increasing Self-Advocacy Among People with Substance Use to Improve Access to Comprehensive Medical Care

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Background

Stigma is a frequently cited barrier to accessing necessary healthcare services among people experiencing substance use. This population is “at increased mortality risk, yet they typically avoid healthcare settings due to stigma and shunning.”¹

In a 2019 survey of individuals in Maricopa County, AZ, 40% of respondents indicated that they “avoided healthcare due to anticipated mistreatment.”² Stigma in medical settings can take many forms: invasive questions, inflexible policies, substandard care, medical gaslighting, and abusive behavior. The negative consequences may include avoiding wellness and preventative care, delaying or forgoing medical care altogether, decreased likelihood of calling emergency medical services in an overdose or other health emergency, and increased use of Emergency Departments (ED) for medical care.

While we continue efforts to reduce stigmatizing attitudes and policies within the healthcare system, we can also work towards improving patients’ readiness to engage with clinicians and staff. Supporting our clients and participants to communicate proactively with providers and sharing practical skills to promote self-advocacy is one strategy for addressing stigma and hesitancy in seeking care. This can equip patients to be more confident and engaged in their

healthcare, support continuity of care, and enable a less stressful care experience.

This resource offers recommendations for direct services providers working with people who use drugs to help them better engage with medical services by promoting health literacy and self-advocacy in medical settings.

Navigating the Clinical Care Continuum

Finding a Provider

Talk with your participants to better understand their goals, concerns, priorities, and motivations for seeking care, including how past experiences have shaped their willingness to engage with services. In helping participants to find a provider, consider the following:

- Ask colleagues and other participants about recommendations for specific providers or offices. Encourage people to ask for referrals within their own personal networks.
- Remind participants that it may not always be possible to choose their provider. Some regions have fewer healthcare facilities or specialty care providers. Insurance plans may only cover care from within their network of providers.

¹ Papalamproukoulo, Z., Ntagianta, E., Triantafyllou, V. et al. Breaking the vicious cycle of delayed healthcare seeking for people who use drugs. *Harm Reduct J* 22, 27 (2025). <https://doi.org/10.1186/s12954-025-0166-3>

² Meyerson BE, Russell DM, Kichler M, Atkin T, Fox G, Coles HB. I don't even want to go to the doctor when I get sick now: Healthcare experiences and discrimination reported by people who use drugs, Arizona 2019. *Int J Drug Policy*. 2021;93:103112. doi:10.1016/j.drugpo.2021.103112

- If seeking care that is not locally available, support with preparation including organizing transportation, childcare, work coverage, and incidental expenses.
- Share any local options for lower-threshold medical facilities for preventative care and screenings, such as mobile testing and screening vans, health care screenings at community health fairs, and vaccine clinics.

Before a medical visit

Ahead of an appointment, especially if there has been a length of time between scheduling and attending, find an opportunity to review and reinforce some of the following reminders about preparing for, navigating, and follow up after a medical visit:

- When scheduling appointments by phone, encourage participants to take notes during the call. Write down the date and time of the conversation, the name of the person they spoke with, the date and time of appointment, the location (including suite numbers and parking or building access instructions), and any other relevant information about preparing for the appointment or what to bring.
- Participants should follow up with the healthcare provider or agency to clarify any preparation or instructions for the appointment. The provider may have a dedicated phone app or other platform for patient information and questions. Patients may be able to submit intake and medical history forms online. Provide computer access if possible and support to complete forms or identify any unknown information for follow-up.

- Assist participants in writing down anything they want to discuss or any information they may need to remember for their appointment. This may include:
 - *List of symptoms and duration*
 - *Current and recent medications*
 - *Relevant family history*
 - *Questions for the provider or other staff*
 - *If receiving take-home medication, information about preferred pharmacy*
 - *For medications for opioid use disorder (MOUD) or any psychiatric medication, name and contact information for the prescriber*
 - *Any other concerns*
- A trusted family member, friend, or other support person may be invited to join an appointment to serve as an observer, notetaker, and/or advocate. If support is not available in-person, they may be able to join by audio or video call (being mindful that some facilities have poor reception or restrictions on where cell phones can be used). If within your scope of services, consider offering to have a staff member join the appointment if appropriate.
- Some medical facilities have peer support available by request. Encourage interested participants to ask if this service is available when scheduling or confirming an appointment.
- Participants on MOUD should ask about medication provision when planning any prolonged medical visits. If needed, they should work with medical staff prior to their visit to develop a care plan.
- Depending on the type of visit, participants may need to be in a waiting room, exam room, or in-patient setting for a long

time. Plan accordingly: bring snacks, warm layers, phone/tablet chargers, entertainment, or other comforts.

During a medical visit

It is understandable to feel overwhelmed or powerless in clinical settings. You can help address these concerns by sharing practical advice, emphasizing that all patients have rights to information, support, and acceptance or refusal of services.

- Encourage patients to bring writing materials or a phone to take notes during the visit.
- Remind people to ask questions about anything they do not understand, including unfamiliar terms or acronyms.
- If visiting a teaching hospital or similar setting and depending on comfort level, patients can request that students not be present for observation during their appointment.
- Be aware that there are certain tests and procedures during which patient advocates or other guests may not be present. For any inpatient care requiring hospitalization, patients should keep track of visiting hours and any related rules.
- Patients do not have to disclose their substance use or any related diagnoses if they feel uncomfortable or unsafe doing so.
- If comfortable disclosing their substance use, patients can ask their medical provider about potential drug interactions with any current or new prescriptions and other potential health effects and prevention strategies.
- If preferred, patients can request to have written materials read aloud.

- Patients may request interpretation and translation services. If possible, identify interpretation and translation needs when scheduling.
- You can discuss and identify any relevant and appropriate disability accommodations with participants before their visit. Accommodation includes access to MOUD for people with a diagnosed substance use disorder.
- Participants have a right to informed [consent](#) when undergoing a medical intervention. This includes the provider sharing information about:
 - *The nature of the procedure or intervention*
 - *The risks and benefits of the procedure or intervention*
 - *Reasonable alternatives*
 - *The risks and benefits of alternatives*
 - *An assessment of the patient's understanding of these elements*
- Patients have a right to agree to or refuse any suggested procedures, interventions, or treatments. If refusing, they will likely be asked to sign an "Against Medical Advice" form.
- Unfortunately, it is possible that refusing care could result in negative treatment from medical staff. It is best to try not to get pulled into a negative exchange or to take such reactions personally.
- If patients feel that they are being treated poorly or in a retaliatory manner by medical staff, they have a right to ask for a different provider. This may not always be possible, but it is still a reasonable request to make.

- If a provider refuses to pursue a potential treatment or follow-up care for any reason, patients may request that the provider document in their chart that the patient was refused treatment and the reason they were refused.
- Patients have a right to adequate pain control regardless of medical history and may ask if they are not proactively offered.
- Patients can request to see their medical records at any time for any reason.
- Patients can end their appointment at any time for any reason.

After a medical visit

Participants may find that increased health literacy in clinical settings results in a more positive and empowering experience. However, if they have a poor experience during a visit, there are channels available to share their complaints or feedback. Offer support to participants with any of the following:

- Be sure to follow up with any questions or clarifications for the provider or other staff. If needed, confirm instructions for any new medications. This may be done before leaving the facility or by phone call after the appointment.
- Patients have a right to additional medical opinions and may seek diagnoses or care from another provider. If insured, patients may want to get clarification from their insurance company on coverage for repeat procedures or appointments.
- Patients have a right to copies of their medical files. However, there may be fees

associated with having records printed and mailed.

- If participants believe that their doctor or other medical providers acted unethically, they can file a complaint to their state [medical board](#).
- If participants have Medicaid or Medicare, the [Center for Medicaid and Medicare Services](#) has instructions on how to file a complaint about provider behavior, improper treatment, and/or unsafe hospital conditions.
- [The Legal Action Center](#) offers several relevant resources, including rights for people visiting an ED for drug- or alcohol-related emergencies.

The takeaway

Direct services providers can help program participants better prepare for interfacing with medical providers. Preparing for visits ahead of time, seeking support, asking questions, and understanding patient rights are all part of improving health literacy and encouraging engagement and retention in medical care.



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