

Guidelines for Questionnaire Screenings



Purpose:

This resource provides health care professionals with guidelines for how to make health screening questionnaires accessible for people with disabilities. This includes questionnaires for things like depression or intimate partner violence.

Introduction

Preventive health screenings for conditions, such as anxiety, depression, substance use disorders, and intimate partner violence, along with routine intake questionnaires and sexual health evaluations, are essential health care tools; however, these questionnaires can present significant barriers for people with disabilities, potentially compromising both the accuracy of collected information and the quality of care provided. While validated screening instruments cannot have their language modified due to copyright restrictions and validation requirements, formatting and administration approaches can be adapted to improve accessibility and reduce trauma.

With approximately 61 million adults in the United States living with a disability, ensuring accessible screening processes is both a legal requirement and a clinical necessity. Accessible screening processes benefit everyone involved: patients can provide more accurate information in a comfortable environment, practitioners can make better-informed clinical decisions, and health care systems can improve efficiency while demonstrating their commitment to inclusive care.

The Americans with Disabilities Act (ADA) requires health care systems to ensure equitable access to health care for people with disabilities, which includes screening tools and questionnaires accessible through reasonable accommodations and effective communication strategies.



Best Practices:

The Ideal Questionnaire Process

The following process represents best practices for inclusive screening that respects patient autonomy while ensuring clinical effectiveness. The strategies outlined in this guide will help practitioners work toward achieving this ideal process:

→ Pre-screening Preparation

Review any accommodations listed in the patient's file and appropriately adjust the appointment, such as increasing visit length, preparing alternative questionnaire formats, making additional staff available to assist, or providing a quiet, less distracting room.

→ Frequency Consideration

Administer questionnaires no more than once every six months unless clinically indicated.

→ Clear Explanation

Explain the purpose of the questionnaire, what will be done with the results, and any legal reporting requirements.

→ Informed Consent

Ask for the patient's consent and offer the option to opt out of the questionnaire.

→ Supported Completion

Allow the patient to complete questionnaires with any supports they may need.

→ Results Discussion

Explain results in plain, nonjudgmental language and check for understanding.

→ Collaborative Follow-up

Work with the patient to develop a follow-up plan based on results when needed, including referrals to accessible specialists experienced in working with people with disabilities.

The strategies for removing barriers and communication techniques described in this resource provide practical tools to implement these best practices in your clinical setting.



Creating Accessible and Inclusive Screening Environments



People with disabilities face significant barriers when completing screening questionnaires in health care settings. These barriers can create gaps in care and ultimately impact health outcomes for populations already experiencing health disparities. Addressing these barriers requires comprehensive changes in how practitioners approach screening, communicate with patients, and follow up on results.

Fear and Mistrust

The Barriers

Patients may avoid honest responses due to well-founded fears about consequences, including getting in legal trouble, having results follow them through their medical records, or having screening results derail their appointment. Cultural factors may also influence their responses. Patients may not trust that practitioners will help them properly, and some have been hurt by the health care system before. This distrust can be particularly heightened with screening questionnaires that ask very personal questions.

What Practitioners Can Do

→ Implement disability and trauma-informed care.

Many patients with disabilities have experienced trauma within health care systems, including discrimination, dismissal of their concerns, painful procedures without adequate support, or being treated as less than human. Recognize that a patient's reluctance or anxiety may stem from previous harmful health care encounters rather than the current screening itself.

Practitioners should:

- Complete disability and trauma-informed training.
- Recognize that people with disabilities may have experienced medical trauma, discrimination, or abuse.
- Understand that screening questions may trigger anxiety, fear, or past traumatic experiences.
- Approach each patient with respect, patience, and cultural humility.



→ Build trust through clear communication.

Transparency about the screening process and its purpose can help reduce patient anxiety and build rapport.

Practitioners should:

- Clearly explain the purpose of the screening and how results will be used. Use plain, easy-to-understand language, avoiding medical jargon and acronyms.
- Clarify who will see the results, including any mandatory reporting requirements before the screening.
- Emphasize confidentiality protections.
- Provide information about available support resources.

→ Respect patient autonomy.

Giving patients control over their participation in screening demonstrates respect for their decision-making capacity and can improve engagement.

Practitioners should:

- Respect patient decisions without judgment or pressure.
- Provide clear opt-out options on both digital and paper versions and allow patients to opt out at any time, even after starting the screening.

See below for two examples of informed consent and opt-out options.

Example 1: Digital Platforms

"We are using this screening to better understand your health needs and connect you with appropriate resources. Completing this screening is optional and will not affect your care if you choose not to participate.

- If you would like to complete the screening, click [CONTINUE]
- If you have already completed this screening or prefer not to participate, click [SKIP]"

Example 2: Paper Forms

"We are using this screening to better understand your health needs and connect you with appropriate resources. Completing this screening is optional and will not affect your care if you choose not to participate.

☐ I have already completed this screening recently or prefer not to complete this screening at this time"

Note: When screenings are required by Centers for Medicare and Medicaid Services (CMS), insurance, or clinic policy, clearly explain this requirement and work with patients to identify accommodations that will support them completing the questionnaire.



Assumptions, Stigma, and Ableism

The Barriers

Practitioners may incorrectly assume that people with disabilities, particularly those with intellectual and developmental disabilities, do not engage in sexual activity or other health behaviors that warrant certain screenings. They may think anxiety and depression are normal parts of having a disability, or that people with intellectual disabilities cannot have mental health conditions. The assumption that disabled people do not need to function at their highest capacity or cannot benefit from treatment represents discrimination that leads to health disparities.

Practitioners may make assumptions about patients when they do not complete the questionnaires, thinking they are being difficult or have something to hide, without realizing the patient may be experiencing distrust due to being harmed by the health care system or a former practitioner. Additionally, practitioners may attribute symptoms or concerns to a patient's disability rather than investigating potential underlying health conditions (i.e., diagnostic overshadowing).



What Practitioners Can Do

→ Maintain a standard of care.

People with disabilities deserve the same standard of care as all patients. Screenings should be offered to everyone who meets clinical criteria; don't skip this test simply because a patient has a disability.

→ Address sensitive screening considerations.

When conducting screenings that may involve stigmatized topics, such as sexually transmitted infections (STI) testing, substance use, or intimate partner violence, avoid making assumptions about a patient's experiences based on their disability. Disabled people, including those with intellectual disabilities and communication differences, engage in the full range of human experiences and deserve respectful, nonjudgmental screening.



→ Use inclusive communication practices.

How practitioners communicate can significantly impact a patient's comfort level and willingness to honestly participate in screenings.

Practitioners should:

- Speak directly to the patient, not to support people or interpreters.
- If you notice or the patient discloses a disability, ask what you can do to help instead of assuming they need help or what would best support them.
- Listen to how patients describe themselves. Some identify as 'disabled person' (identity first) while others prefer 'person with disabilities' (person first). Ask them if you are unsure.
- Do not assign disability labels. Some patients may not identify as having a disability even if they receive disability-related services.
- Respect chosen names and pronouns and update electronic health records when possible.

→ Implement a support person protocol.

Before beginning sensitive screenings, clarify with the patient whether they want their support person to remain present. Use clear, direct language: "Would you prefer to complete this screening privately?" Respect the patient's choice and provide private space when requested.

Remember that some patients may need their support person for communication or mobility assistance while still wanting privacy for sensitive topics.



Inadequate Follow-up

The Barriers

Practitioners may fail to properly follow up based on questionnaire results. They may not give the full screening, ignore positive results, or give medication without offering counseling. While wait times for mental health appointments may be exceedingly long, and there may not be enough mental health practitioners, practitioners may not take the time to explain this to the patient, leaving them wondering what the next steps are. Additionally, some patients are asked to complete the questionnaire at every visit without any follow up, creating additional distrust.



What Practitioners Can Do

→ Review screening results with the patient.

Regardless of whether results are positive or negative, review the screening results with the patient. Use clear, nonjudgmental language to explain what the results mean and what the next steps are.

Practitioners should:

- Ask open-ended questions to better understand specific needs and concerns:
 - “Your screening shows that you may be experiencing some symptoms of anxiety. Many people find it helpful to talk with a counselor about these symptoms. What are your thoughts about this?”
- Validate their experiences and emphasize that help is available, and they deserve support.
- Clearly address mandatory reporting by telling them what you are required to report, what the reporting process is, and how they will be supported.

→ Develop a comprehensive follow-up plan.

Work with the patient to develop a follow-up plan that respects their preferences and needs. If time is prohibitive, practitioners can collaborate with staff members, such as social workers, case managers, or care coordinators, to develop a follow-up plan, including:

- Ask about their goals and what type of support they would find most helpful.
- Consider the patient’s disability-related needs when making referrals or recommendations.
- Include the patient’s support system if they wish and if appropriate.





→ **Make appropriate referrals.**

Effective referrals require understanding both the patient's needs and accessibility of available resources.

Practitioners should:

- Consider offering several types of support, including counseling, support groups, peer support, and medication management.
- Consider telehealth services if transportation is a barrier.
- Find mental health practitioners experienced in working with people with disabilities.
- Create a referral network of practitioners who understand the intersection of disability and mental health, substance use, and/or intimate partner violence.
- Verify that practitioners in your referral network are accessible in terms of physical accessibility and communication methods.
- Remind patients to check with their insurance if specialists are in-network before their appointment.
- Explain what will happen next and any expected timelines while being transparent about wait times and system limitations.

Access and Accommodations

The Barriers

Appointments may be too short for patients to complete the questionnaires with enough time to discuss results or the primary purpose of the visit. The questionnaire may pose accessibility challenges if the office is unprepared to provide assistance in reading or answering questions.



What Practitioners Can Do

→ Optimize your communication approach.

Clear, accessible communication is fundamental to successful screening and can reduce barriers for all patients.

Practitioners should:

- Use plain, easy-to-understand language with sentences less than 10 words, and avoid medical jargon and acronyms.
- Speak at a moderate pace to allow for processing time.
- Pay attention to your body language. Maintain open posture, appropriate eye contact, and a calm demeanor.
- Respect communication preferences and styles. Some patients may need more time to process, use different communication methods, or show stress through body language.
- Check your understanding regularly: “Let me make sure I understand what you’re telling me ...”
- Regularly check the patient’s understanding using the teach-back method.

→ Provide adequate time and support.

Screenings may take additional time, particularly for patients who need additional support.

Practitioners should:

- Anticipate an extended appointment to complete the screening and discuss results.
- Be prepared to provide assistance with reading or answering questions.
- Allow flexibility in how and when questionnaires are completed. Consider offering patients the chance to complete questionnaires prior to the appointment.
- Offer multiple formats and accommodation options, as needed.

Conclusion

Creating accessible screening environments is not only about compliance, but also provides equitable, high-quality care that meets the needs of all patients. When practitioners implement these strategies, they contribute to a health care system that serves everyone, regardless of disability status.



Screening for All



**Making preventive health screenings
accessible for everyone.**

More resources available at
mcd.org/screening-for-all



Screening For All is an initiative funded by the Centers for Disease Control and Prevention (CDC)'s National Center on Birth Defects and Developmental Disabilities (NCBDDD) to address the significant barriers people with disabilities face in accessing preventive health screenings.

Developed by MCD Global Health, this project provides patients and health care practitioners with evidence-based tools and resources to make preventive health screenings accessible to all patients. Questions or comments can be sent to info@mcd.org.

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