

Research to Improve the Delivery of Clinical Preventive Services to People with Disabilities

Technical Report

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Executive Summary

The Joint Explanatory Statement that accompanied the Consolidated Appropriations Act, 2023, included \$750,000 for the Agency for Healthcare Research and Quality (AHRQ) to "develop a research agenda and report for dissemination on health promotion, disease prevention, and intervention strategies for people with disabilities." In response, AHRQ leveraged its capabilities in evidence synthesis and stakeholder/partner convenings to identify evidence gaps and research priorities.

This work identified three primary research needs to understand how to better deliver clinical preventive services to people with disabilities:

- Research at the **healthcare system level**, including a focus on the contexts within which care is delivered; on care teams and communities; and on systems-change research;
- Research on **educating clinicians and healthcare organizations**, including developing and assessing the impact of educational interventions; and
- Research on **data and methods**, including how to best collect data on disability status and experiences and how to collect data on clinician knowledge and bias.

These efforts also highlighted three guiding principles for future research:

- Ensuring inclusion and meaningful engagement of the disability communities throughout the research process;
- Building relationships and trust between researchers and people with disabilities; and
- Recognizing the variation that exists among people with disabilities.

Furthermore, this work identified changes needed in the research infrastructure, such as longerterm support for building relationships and trust between research teams and disabled people and the inclusion of people with disabilities on the study sections that review grant applications.

The research needs and guiding principles outlined in this report create a high-level framework for the federal government and others to use to support impactful and trusted research that can improve quality and efficiency in the delivery of clinical preventive services to disabled people. A coordinated federal effort could systematically identify current and future work that might address identified research gaps. Such work can enable greater access to the health promotion and risk reduction benefits of preventive care among people with disabilities.

Background

The Joint Explanatory Statement that accompanied the Consolidated Appropriations Act, 2023, included \$750,000 for the Agency for Healthcare Research and Quality (AHRQ) to "develop a research agenda and report for dissemination on health promotion, disease prevention, and intervention strategies for people with disabilities." In response, AHRQ leveraged its capabilities in evidence synthesis and stakeholder/partner convenings to identify evidence gaps and research priorities. Addressing these gaps and priorities will require a broad effort across the U.S. government and private funders.

Clinical preventive services, which are essential to ensure health promotion and disease prevention, are the focus of this technical report. These services involve the use of screening, counseling, medications, or vaccines to prevent disease and help people live healthier lives. Despite having the same need for clinical preventive services as people without disabilities, people with disabilities may be less likely to receive these services. Research has demonstrated, for example, the existence of this gap for breast and cervical cancer screening; screening for high cholesterol, high blood pressure, and tobacco/nicotine use; the receipt of nutrition and exercise counseling; and the receipt of vaccinations.¹⁻¹⁴ Recognizing that these and other gaps in care delivery may have negative impacts on the health of disabled people, the disability communities in the United States have long advocated for improved access and quality of healthcare services designed to meet the needs of disabled people.

To address this issue, AHRQ commissioned an Evidence-based Practice Center (EPC) evidence review to synthesize and report the current research findings in this area. AHRQ then convened a panel on May 9, 2024, to discuss the report's findings and identify gaps where additional research is needed. The panel was composed of 13 individuals bringing a combination of professional experience, research background, and personal experience living with one or more disabilities. This report focuses on the research needed to understand how to improve the delivery of clinical preventive services to people with disabilities.

EPC Report

The EPC report, entitled "<u>Healthcare Delivery of Clinical Preventive Services for People with</u> <u>Disabilities</u>," assessed the evidence on barriers and facilitators to the delivery of clinical preventive services to disabled people and the effectiveness of interventions to improve the receipt of such services. The report included research on a broad range of general categories of disability in children and adults, including physical, cognitive/intellectual/developmental, sensory, and psychiatric disabilities, and numerous specific populations of interest. It focused on 20 high-priority clinical preventive services with <u>Grade A or B recommendations</u> from the U.S. Preventive Services Task Force (see Appendix A). The EPC <u>literature search</u> found more than 11,000 references to potentially relevant studies published between 1990 and 2023. Further review of those references yielded 54 studies on the barriers to and facilitators of the delivery of clinical preventive services to disabled people. Of these, 16 were studies of interventions to improve the receipt of such services. The intervention studies, some of which were characterized by small sample sizes, focused on educational interventions targeting individual people with disabilities.

Panel Discussion of the EPC Report

The panel discussion began with reactions to the draft EPC report. Panel members highlighted the scarcity of research in this area, as evidenced by the limited number of relevant studies identified. Panel members expressed concern that the intervention studies were focused on educating individual people with disabilities about clinical preventive services and/or on ways they could advocate for the receipt of these services while few studies examined interventions that addressed how clinicians, healthcare organizations, or systemic issues impact the delivery of clinical preventive services to disabled people.

In addition, the panel noted the diversity of the population of people with disabilities (including diversity in disability type, functional status, socioeconomic position, and race), and that the studies reflected a lack of emphasis on the personal experiences that people with disabilities have when seeking preventive care. The studies also lacked assessments of bias or ableism (discrimination or prejudice against disabled people) on the part of clinicians, care teams, and healthcare organizations and of the influence such bias or ableism has on the accessibility of care. Furthermore, the studies did not focus on the ways in which ableism is embedded in the healthcare system and how ableism impacts the quality of care for people with disabilities.

Research Needs

The panel identified research gaps focused on (1) systems of care and (2) the education of clinicians and healthcare organizations to increase awareness of how to make care more accessible to people with disabilities. The panel also identified the data and methods required to enable such research.

Systems Research

Research at the healthcare system level includes a focus on the social, cultural, structural, and environmental contexts within which care is delivered; on care teams and communities; on payment for healthcare services; and on using systems-change research approaches to understand how to better deliver clinical preventive services to people with disabilities.

Social, Structural, Cultural, and Environmental Contexts

Many social, structural, cultural, and environmental barriers within and outside the healthcare system may affect the delivery of clinical preventive services to people with disabilities. Research questions to be addressed include the following:

- What structural and environmental barriers do disabled people face in their interactions with the healthcare system? How do these differ based on the nature of the disability? How should data on these barriers be collected?
- How do these structural and environmental barriers affect the delivery of clinical preventive services to people with disabilities?
- What strategies and approaches successfully reduce the impact of these barriers on the delivery of clinical preventive services?
- How do social needs—such as transportation and housing—affect the delivery of clinical preventive services to people with disabilities?
- What interventions effectively mitigate the impact of unmet social needs (including variability in these needs based on local context, such as rurality, weather extremes, or resource limitations) on the delivery of clinical preventive services?

Care Teams and Communities

- Given that racially concordant clinical care teams have been shown to improve the care for patients from historically excluded, underserved communities, what impact would care teams that include clinicians with disabilities have on improving the delivery of clinical preventive services to patients with disabilities?
- What impact do peer navigators, peer health workers, practice-based care navigators, community navigators, promotoras, or community health workers have on improving the delivery of clinical preventive services to people with disabilities?
- How do community-designed/community-led systems-focused interventions differ from interventions designed by researchers or healthcare organizations? What impact do such interventions have?

Paying for Healthcare Services

- What additional time and/or clinical resources (including equipment and needed changes to building design) are required to deliver clinical preventive services to disabled people? What billing and reimbursement changes are needed to support them?
- What is the impact of billing and reimbursement changes on the delivery of clinical preventive services to disabled people?

Research to Improve Care Delivery at the System Level

• Large, system-level improvements in healthcare delivery—such as fostering changes in healthcare culture to improve inclusivity of people with disabilities or coordination between healthcare and long term services and supports—are complex to implement and nonlinear in nature, given uncontrollable shifts in system priorities or the broader

health policy environment. This makes it difficult to measure and attribute improvements in outcomes using traditional research approaches. How can <u>realist approaches to</u> <u>evaluation</u>, which focus on identifying mechanisms or contexts that encourage change rather than formally demonstrating cause and effect, help assess the impact of large, multi-factorial approaches to making healthcare more inclusive for people with disabilities?

Educating Clinicians and Healthcare Organizations

The EPC report found no studies of interventions designed to improve the knowledge and skills of clinicians or care teams that deliver clinical preventive services to people with disabilities. The panel identified this gap as an area of opportunity and encouraged research on the effectiveness of such interventions.

Potential research areas include the following:

- Educational interventions
 - Develop and assess the impact of educational interventions to increase knowledge and to reduce bias and ableism among clinicians and care teams.
 - Develop and assess the impact of educational interventions to improve communication between clinicians/care teams and patients with disabilities.
- Methods
 - Develop methods to measure short- and long-term outcomes for educational interventions that are designed to reduce bias and ableism among clinicians and care teams.
 - Develop methods to assess provider knowledge about disabilities and the delivery of clinical preventive services to disabled people.
- Test impact
 - Test the impact of multi-level interventions (e.g., at the system-wide and practice level), such as those that both increase the length of time that clinicians spend with patients and address clinicians' implicit and explicit biases.
 - Test the impact on the delivery of clinical preventive services of having people with disabilities serve as educators for clinicians and of having people with disabilities working in medical settings.

The panel emphasized the importance of developing and studying the impact of educational interventions for clinicians at all levels, from trainees to experienced personnel.

Data and Methods

Rigorous research on the delivery of clinical preventive services is not possible without highquality data and methods. Challenges, gaps, and research questions are described in the following table.

Challenge or Gap	Research Questions		
Collecting Data on Disability Status and Experiences			
Inconsistent approaches to data collection on disability status Little data are available on	 What are the most rigorous, practical approaches to collecting disability status as a demographic characteristic in surveys to better enumerate the U.S. population with disabilities? What are the most rigorous, practical approaches to collecting disability status as a consistent, discrete field in electronic health records? What sub-populations of people with disabilities need 		
sub-populations	to be consistently identified in research studies, and what are the most rigorous and practical approaches to doing so?		
Need to engage people with disabilities to understand drivers of trust Need for tools to help capture the patient perspective	 What factors influence the willingness of people with disabilities to share their data for research? What safeguards might mitigate mistrust? What tools do clinicians and researchers need to support a shift away from relying on caregiver perspectives as proxies and toward direct data collection from disabled people whenever possible? 		
Collecting Data on C	linician Knowledge, Attitudes, Ableism, and Bias		
Need for more data on clinician and care team knowledge and attitudes Lack of data on ableism and bias	 What are the best approaches to collecting data on clinician and care team knowledge of and attitudes related to providing healthcare to people with disabilities? How might working definitions and measures of ableism at the clinician- and healthcare systems-level best be developed for use in research studies? 		
Collecting Data on Context and Accommodations			
Lack of data on patients' situational context	 What data on social needs, such as transportation, housing, and food access, are needed to conduct research in this area? What other data are needed about the environments in which disabled people live and those in which they receive their healthcare? 		
Lack of data on reasonable accommodations (disability- related adjustments or modifications to healthcare practices, procedures, or facilities)	 How might data on reasonable accommodations requested within the healthcare system best be captured in electronic health records and in survey research? How might data on whether reasonable accommodation requests are fulfilled best be captured in electronic health records and survey research? 		

Developing Methods to Enable Comparisons		
Need for methods to enable	What are the most appropriate methods for	
consistent, appropriate	categorizing types of disabilities within datasets to	
comparisons	enable consistent comparisons, including how and	
	when to categorize disability based on diagnosis, self-	
	identification, and/or functional category?	

The panel also emphasized the following:

- The importance of requiring data collection on disability status rather than this being an optional data element—for example, developing requirements for the collection of disability status consistent with the <u>United States Core Data for Interoperability</u> standard set in work done by grantees of AHRQ, the Health Resources and Services Administration, and the National Institutes of Health;
- The need to define a roadmap for capturing needed data elements and to address concerns that data collection is costly and will require dedicated funding;
- The benefits of exploring data harmonization to enable the analysis of data from multiple studies with small sample sizes; and
- The need for more qualitative data integrated into research studies, including oral histories and interviews, to better understand the lived experience of people with disabilities.

Guiding Principles for Future Research

The discussions suggested three foundational principles to guide future research on the delivery of clinical preventive services to people with disabilities, as follows:

1. Ensure inclusion and meaningful engagement throughout the research process.

- a. Research projects should be developed by and in collaboration with disability communities to ensure that the research is relevant to their collective interests.
- b. Research about people with disabilities should include disabled people in the implementation, analysis, and evaluation phases. This includes ensuring that people with disabilities are members of research teams, are employed by research funders and involved in directing research funding, and are included in study sections that review grant applications for research projects.

2. Build relationships and trust.

- a. Relationship building between researchers and people with disabilities requires dedicated time and funding to bring all parties to the table as equal partners.
- b. To ensure that trust is well-founded, appropriate privacy protections and clear limitations on the use of data collected for research, healthcare, and other purposes need to be in place to address concerns that disabled people may have about their

data being shared or disclosed without their consent. This includes data in the healthcare environment (e.g., in electronic health records) and in the consumer environment (e.g., purchases that may signal the presence of a disability, such as for hearing devices or adult diapers).

3. Recognize the variation that exists among people with disabilities.

- a. Disabled people have a broad range of experiences, health goals, and interactions with the healthcare system. Research needs to account for this variation and avoid grouping disabilities into overly broad categories that may obscure important differences (e.g., creating a "sensory disability" category that combines people who are blind or have low vision with people who are deaf or hard of hearing).
- b. Research should examine <u>discrimination experienced by people with disabilities using</u> <u>an intersectional perspective. An intersectional perspective considers the varied</u> experiences of discrimination people with disabilities may encounter that may be related to the presence of multiple disabilities or identities; for example, intersectional research on disability discrimination may consider the unique experience of those who are both a member of a historically excluded, underserved community and have a disability.
- c. Depending on where they live, some disabled people may disproportionately face community-based challenges to receiving preventive services. For example, rural areas have higher proportions of residents with disabilities than urban areas and more limited healthcare availability.
- d. Because clinical preventive services are recommended throughout the life course, research should ensure a focus on children and adults of all ages and how their experiences, health goals, and interactions with the healthcare system differ.

Moving to Action

Changes to Research Infrastructure

While discussing research needs, the panel also identified needed changes to the existing research infrastructure to better identify interventions that will improve the delivery of clinical preventive services to people with disabilities. These include the following:

- Longer-term support for building relationships and trust between research teams and disabled people;
- The inclusion of scientists with disabilities on research teams;
- The inclusion of disability communities in developing research questions and projects;
- The growth of community-designed and community-led interventions; and
- The presence of disabled people on study sections that review research grant applications.

Each of these items could be measured by funders, and trends could be examined and shared to assess progress in these areas.

Panelists also noted challenges with obtaining funding to conduct systems-change research as described above. They noted that systems-level interventions are costly to implement, that study sections reviewing grant applications may lack people with lived experience or experience with such interventions, and that funders can be reluctant to fund complex, innovative research designs that examine multi-level interventions.

Taking Action

The panel highlighted the urgent need for moving from talk to action, particularly by shortening the time between research and policy development to improve access to and delivery of clinical preventive services to people with disabilities. The panel urged consideration of existing barriers to change that have limited the advancement of research on care for people with disabilities for many years. Their discussions pointed to three areas of focus to help move the field forward.

Partner with Disability Communities

In keeping with the guiding principle of ensuring inclusion in the research process, it is essential that the federal government partner with disability communities to set research priorities, ensuring that prioritization involves a broad range of disabled people who have different needs and differing experiences with the healthcare system.

Consensus-Based Action

Panelists noted that not all actions require rigorous research. Rather, some improvements can be determined by consensus. For example, one panelist noted that research is not required to prove that having physically accessible mammography machines is necessary to enable people with certain physical disabilities to receive mammograms.

Improving Care for All

Members of the panel noted that interventions to improve the delivery of clinical preventive services to people with disabilities have the potential to transform care for all patients. For example, an intervention that successfully improves clinician communication with patients with disabilities about such services could improve how clinicians communicate with all of their patients.

More broadly, a focus on universal design—in which products, services, and environments are designed to be usable by all people without the need for adaptation—has the potential to improve the delivery of clinical preventive services to people with disabilities and to those without disabilities. Curb cuts are one well-known example of universal design. While originally created to enable wheelchair access for street crossing, curb cuts also benefit people with wheeled suitcases, strollers, and delivery carts.

Conclusion

The recommendations presented here are based on the discussions of this panel and do not necessarily take into account recently published, ongoing, or new research or regulations. Absent a coordinated federal response to this broad topic, it is difficult to systematically identify the current/ongoing body of work that might address some of the research gaps identified in this report. That said, the research needs and guiding principles outlined in this report create a high-level framework for the federal government and others to use to support impactful and trusted research that can improve quality and efficiency in the delivery of clinical preventive services to disabled people. In doing so, this research may enable greater access to the health promotion and risk reduction benefits of preventive care among people with disabilities.

Acknowledgments

AHRQ would like to thank the panel members and the federal partners who attended this meeting. Some of the federal partners reviewed an earlier draft of this document. Please see Appendix B for information on the panel members and Appendix C for information on the federal partners.

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Appendix A: U.S. Preventive Services Task Force Letter Grades

The U.S. Preventive Services Task Force (USPSTF) assigns one of five letter grades (A, B, C, D, or I) based on the available evidence.

Grade	Definition
А	The USPSTF recommends the service. There is high certainty that the net
	benefit is substantial.
В	The USPSTF recommends the service. There is high certainty that the net
	benefit is moderate or there is moderate certainty that the net benefit is
	moderate to substantial.
С	The USPSTF recommends selectively offering or providing this service to
	individual patients based on professional judgment and patient preferences.
	There is at least moderate certainty that the net benefit is small.
D	The USPSTF recommends against the service. There is moderate or high
	certainty that the service has no net benefit or that the harms outweigh the
	benefits.
I Statement	The USPSTF concludes that the current evidence is insufficient to assess the
	balance of benefits and harms of the service. Evidence is lacking, of poor
	quality, or conflicting, and the balance of benefits and harms cannot be
	determined.

Additional information is available at

https://www.uspreventiveservicestaskforce.org/uspstf/about-uspstf/methods-and-processes/grade-definitions.

Appendix B: Panel Members

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