

# *Draft Systematic Review*

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Number xx

## **Healthcare Delivery of Clinical Preventive Services for People with Disabilities**

**Prepared for:**

Agency for Healthcare Research and Quality  
U.S. Department of Health and Human Services  
5600 Fishers Lane  
Rockville, MD 20857  
www.ahrq.gov

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**Prepared by:**

[To be included in the final version of the report.]

**Investigators:**

[To be included in the final version of the report.]

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## Preface

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Robert Otto Valdez, Ph.D., M.H.S.A.  
Director  
Agency for Healthcare Research and Quality

Therese Miller, D.P.H.  
Director  
Center for Evidence and Practice  
Improvement  
Agency for Healthcare Research and Quality

Christine Chang, M.D., M.P.H.  
Director  
Evidence-based Practice Center Program  
Center for Evidence and Practice  
Improvement  
Agency for Healthcare Research and Quality

David W. Niebuhr, M.D., M.P.H., M.S.  
Task Order Officer  
Center for Evidence and Practice  
Improvement  
Agency for Healthcare Research and Quality

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## **Key Informants**

In designing the study questions, the EPC consulted several Key Informants who represent the end-users of research. The EPC sought the Key Informant input on the priority areas for research and synthesis. Key Informants are not involved in the analysis of the evidence or the writing of the report. Therefore, in the end, study questions, design, methodological approaches, and/or conclusions do not necessarily represent the views of individual Key Informants.

Key Informants must disclose any financial conflicts of interest greater than \$5,000 and any other relevant business or professional conflicts of interest. Because of their role as end-users, individuals with potential conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any conflicts of interest.

The list of Key Informants who provided input to this report will be added to the final version of the report.

## **Technical Expert Panel**

In designing the study questions and methodology at the outset of this report, the EPC consulted several technical and content experts. Broad expertise and perspectives were sought. Divergent and conflicting opinions are common and perceived as healthy scientific discourse that results in a thoughtful, relevant systematic review. Therefore, in the end, study questions, design, methodologic approaches, and/or conclusions do not necessarily represent the views of individual technical and content experts.

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The list of Peer Reviewers will be added to the final version of the report.

# Healthcare Delivery of Clinical Preventive Services for People with Disabilities

## Structured Abstract

**Objectives:** The purpose of this review is to (1) document and summarize barriers and facilitators to the receipt of clinical preventive services among people with disabilities; and (2) evaluate the literature on the effectiveness of interventions to improve the receipt of clinical preventive services among people with disabilities.

**Data Sources:** We performed searches in electronic databases (Ovid<sup>®</sup>, MEDLINE<sup>®</sup>, PsycINFO<sup>®</sup>, Embase<sup>®</sup>, the Cochrane Central Register of Controlled Trials, and EBSCO CINAHL Plus) from 1990, the year of passage of the Americans with Disabilities Act (ADA), through November, 2023; manual review of reference lists; suggestions from stakeholders; and responses to a Federal Register Notice.

**Review Methods:** Following the Agency for Healthcare Research and Quality Methods Guide (available at: <https://effectivehealthcare.ahrq.gov/products/collections/cer-methods-guide>), the review methods were determined a priori and a protocol was developed through collaboration with Federal partners, Key Informants, and a Technical Expert Panel. We used predefined criteria for independent dual review of abstracts and full-text articles to determine inclusion of studies related to 20 clinical preventive services with Grade A or Grade B recommendations by the U.S. Preventive Services Task Force. We assessed individual studies for general quality (studies of barriers/facilitators) or risk of bias (effectiveness studies) using dual review and criteria specific to the different study designs. Predefined data from studies were abstracted into tables by one reviewer and verified by a second reviewer. Barriers and facilitators were classified into seven general categories (environment-level, person-level, provider-level, healthcare system-level, accessibility of healthcare facility, accessible communication, and policy-level). Barriers/facilitators and interventions were described and presented for each preventive service according to general types of disability (physical, cognitive/intellectual/developmental, sensory, and serious psychiatric/mental illness). Due to high methodological/clinical heterogeneity of the studies and limited available data, we did not assign strength of evidence ratings or conduct meta-analyses.

**Results:** Of 11,010 references, we included 68 studies – 54 reported on barriers/facilitators and 16 reported on the effectiveness of interventions. For barriers/facilitators and for the effectiveness of interventions, evidence was lacking for most preventive services and generally limited to one or two types of disability for any given preventive service. Studies on barriers/facilitators were related to 10 of the 20 preventive services included in the review, and studies on the effectiveness of interventions were related to 8 of the 20 preventive services. Most evidence was for two preventive services – breast cancer screening and cervical cancer screening. For breast and cervical cancer screening, studies reported on most categories of barriers/facilitators and included all types of disability; for other preventive services, fewer studies reported fewer categories of barrier/facilitator and fewer types of disability. Limited evidence from three trials found various educational and health advocacy interventions to be

associated with increased rates of breast and cervical cancer screening among women with physical disabilities, cognitive/intellectual/developmental disabilities, and serious mental illness.

**Conclusions:** We found limited evidence on barriers and facilitators to the receipt of most clinical preventive services among people with disabilities, and especially limited evidence on interventions to improve the receipt of those preventive services. Most studies were related to breast and cervical cancer screening. The lack of studies for most preventive services and types of disability underscores the need for research to address the substantial gaps in the evidence.

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# Executive Summary

## Main Points

- Studies on barriers and/or facilitators to the receipt of clinical preventive services among people with disabilities are lacking for most preventive services and most types of disability.
- By far, the largest number of studies on barriers/facilitators have been related to the receipt of breast cancer screening and/or cervical cancer screening.
- For breast and cervical cancer screening, studies reported on most categories of barriers/facilitators and included all types of disability; for other preventive services, fewer studies reported fewer categories of barrier/facilitator and fewer types of disability.
- Evidence on interventions to improve the receipt of clinical preventive services among people with disabilities is especially limited, with most studies also related to breast and cervical cancer screening.
- Limited evidence from three trials found various educational and health advocacy interventions to be associated with increased rates of breast and cervical cancer screening among women with physical disabilities, cognitive/intellectual/developmental disabilities, and serious mental illness.
- Evidence on interventions to improve the receipt of other preventive services is more limited, with no clear effect of the interventions for any preventive service.

## Background and Purpose

People with disabilities are a substantial portion of the population. Although it has long been recognized that people with disabilities have at least the same need for health maintenance and preventive services as the general population, long-standing disparities in the receipt of various clinical preventive services persist among people with disabilities. The purpose of this systematic review was to document and summarize reported barriers and facilitators to the receipt of selected clinical preventive services among people with disabilities, and to identify and synthesize the literature on the effectiveness of interventions to improve the receipt of selected clinical preventive services among people with disabilities. The review is intended for the target audiences of policymakers, healthcare organizations, advocates for people with disabilities, and researchers, to help guide and inform efforts to address disparities in the receipt of clinical preventive services among people with disabilities. Agency for Healthcare Research and Quality (AHRQ) will be supporting a follow-on stakeholder meeting to discuss the findings of this review and develop recommendations for future research.

## Methods

The Key Questions that guided this systematic evidence review were included with a scope of work issued by AHRQ and revised through a formal topic refinement process. Consistent with the AHRQ Methods Guide for Effectiveness and Comparative Effectiveness Reviews (available at: <https://effectivehealthcare.ahrq.gov/products/collections/cer-methods-guide>), the review methods were determined a priori and a protocol was developed through collaboration with Federal partners, Key Informants, and a Technical Expert Panel. Detailed methods including the search strategies are described in the full report. We used predefined criteria for independent

dual review of abstracts and full-text articles to determine inclusion of studies related to 20 clinical preventive services with Grade A or Grade B recommendations by the U.S. Preventive Services Task Force (USPSTF). We assessed individual studies for general quality (studies of barriers/facilitators) or risk of bias (effectiveness studies) using dual review and criteria specific to the different study designs. Barriers and facilitators were classified into seven general categories (environment-level, person-level, provider-level, healthcare system-level, accessibility of healthcare facility, accessible communication, and policy-level). Barriers/facilitators and interventions were described and presented for each preventive service according to general types of disability (physical, cognitive/intellectual/developmental, sensory, and serious psychiatric/mental illness). Due to high methodological/clinical heterogeneity of the studies and limited available data, we did not assign strength of evidence ratings or conduct meta-analyses.

## Results

Of 11,010 references, we included 68 studies – 54 reported on barriers/facilitators (Key Question 1) and 16 reported on the effectiveness of interventions (Key Question 2). Two studies had limited evidence for Key Question 3 (regarding the effectiveness of particular characteristics or components of interventions), and one study had limited evidence on the harms of interventions (Key Question 4). For barriers/facilitators and for the effectiveness of interventions, evidence was lacking for most preventive services and generally limited to one or two types of disability for any given preventive service.

### Key Question 1. What are the primary barriers and facilitators to the receipt of clinical preventive services among people with disabilities?

Studies that reported on barriers and/or facilitators (n=54) were related to 10 of the 20 preventive services included in the review: screening for anxiety disorder in adults (n=1); breast cancer screening (n=36); cervical cancer screening (n=19); colorectal cancer screening (n=6); screening for depression risk in adults (n=3); screening for HIV infection (n=1); screening for unhealthy alcohol use (n=2); interventions for falls prevention in community-dwelling older adults (n=1); counselling for healthy diet and physical activity for cardiovascular disease (CVD) prevention (n=1); and behavioral counselling to prevent sexually transmitted infections (n=3).

The largest number of studies were related to barriers/facilitators for the receipt of breast cancer screening (69%) and/or cervical cancer screening (35%), and addressed barriers/facilitators for people with cognitive/intellectual/developmental disabilities (47%) or physical disabilities (36%). Table G-1 in Appendix G presents the included studies according to the clinical preventive service(s) and type(s) of disability addressed.

For **breast cancer screening**, most categories of barriers/facilitators (environment-level, person-level, provider-level, healthcare system-level, accessibility of healthcare facility, and accessible communication) were reported for all types of disability. Among women with **physical disabilities**, most reported barriers were at the person-level (e.g., difficulty standing still, fear and/or embarrassment), the provider-level (e.g., ableism, lack of knowledge about people with disabilities) and the level of the healthcare system (e.g., difficulty booking/attending appointments). Most reported facilitators were at the provider-level (e.g., knowledge about people with disabilities). Among women with **cognitive/intellectual/ developmental disabilities**, most reported barriers were at the environment-level (e.g., family/caregiver feeling overwhelmed, transportation), the person-level (e.g., fear and/or embarrassment, inability to give informed consent), and the provider-level (e.g., lack of knowledge about people with disabilities,

not assessing the need for a decision-making delegate). Most reported facilitators were at the person-level (e.g., feeling in control, having coping strategies), the provider-level (e.g., allowing preparatory visits, providing explanations before the procedure), and the level of the healthcare system (e.g., extra time for appointments).

For **cervical cancer screening** among women with **physical disabilities**, most reported barriers were at the person-level (e.g., feeling dependent on others, pain or discomfort with screening) and the provider-level (e.g., negative attitude/ableism, not listening to the person with disabilities). Most reported facilitators were at the provider-level (e.g., assistance with dressing, knowledge about people with disabilities). Among women with **cognitive/intellectual/developmental disabilities**, most reported barriers were at the person-level (e.g., inability to give informed consent, not understanding the screening process) and the provider-level (e.g., ableism, misconceptions about sexual activity and need for screening). Most reported facilitators were at the provider-level (e.g., adjusting procedures to accommodate the patient, providing an explanation before the procedure).

The studies on **colorectal cancer screening** pertained to people with **physical disabilities** or people with **serious mental illness**. Most categories of barriers/facilitators (environment-level, person-level, provider-level, healthcare system-level, and accessibility of healthcare facility) were reported for both types of disability; no barriers or facilitators within the categories of accessible communication or policy were reported for either type of disability.

For the other preventive services, fewer studies reported fewer categories of barrier/facilitator and fewer types of disability. (See Table G-1 in Appendix G for details).

## Key Question 2. What is the effectiveness of interventions to improve the receipt of clinical preventive services among people with disabilities?

Studies on the effectiveness of interventions to improve the receipt of clinical preventive services for people with disabilities (n=16) were related to 8 of the 20 preventive services included in the review: breast cancer screening (n=8); cervical cancer screening (n=9); colorectal cancer screening (n=3); screening for depression risk in adults (n=1); screening for hypertension (n=4); screening for prediabetes/type 2 diabetes (n=1); interventions for falls prevention in community-dwelling older adults (n=1); and interventions for weight loss to prevent obesity-related morbidity (n=2). Seven of the studies assessed multiple clinical preventive services. The studies included seven randomized controlled trials (RCTs), seven nonrandomized studies of intervention (NRSIs), and two cross-sectional studies.

Studies pertained to people with physical disabilities (n=3); cognitive, intellectual, or developmental disabilities (n=8); sensory disabilities (n=4); and serious mental illness (n=1); including 10 studies of interventions directed at people with disabilities, two studies of interventions for clinicians, and four studies of multicomponent interventions targeting both people with disabilities and clinicians. The largest number of studies were of interventions to improve the receipt of breast cancer screening (50%) and/or cervical cancer screening (56%), and pertained to people with cognitive/intellectual/developmental disabilities (50%), sensory disabilities (25%), or physical disabilities (19%).

Randomized controlled trials on **breast cancer screening** generally found educational and health advocacy interventions to be associated with increased receipt of screening, although risk estimates were not consistently statistically significant. Among women with **cognitive/intellectual/developmental disabilities**, one cluster RCT found an educational and self-advocacy intervention targeting general preventive care to be significantly associated with

receipt of screening mammography within 1 year. Among women with **serious mental illness**, one RCT found a 1-year, multicomponent intervention of education and social skills training targeting general preventive care to be significantly associated with receipt of screening mammography within 3 years. Among women with **physical disabilities**, one RCT found an educational intervention designed to improve breast and cervical cancer screening to be associated with a slightly increased probability of receipt of mammography after 6 months (relative risk [RR] 1.16), a difference that was not statistically significant. One RCT of an educational intervention designed to improve breast cancer screening among women with a **sensory disability** (deafness) did not find a significant difference in the receipt of mammography after 1 year.

Randomized controlled trials on **cervical cancer screening** generally found educational and health advocacy interventions to be associated with increased receipt of screening. Three interventions described above for breast cancer screening also targeted cervical cancer screening. Among women with **physical disabilities**, one RCT found an educational intervention designed to improve breast and cervical cancer screening to be significantly associated with higher receipt of a Pap test within 6 months. Among women with **cognitive/intellectual/developmental disabilities**, one RCT found an educational and self-advocacy intervention targeting general preventive care to be significantly associated with receipt of a Pap test within 1 year. Among women with **serious mental illness**, one RCT found a 1-year, multicomponent intervention of education and social skills training targeting general preventive care to be significantly associated with receipt of a Pap test within 3 years. One nonrandomized trial of an educational intervention specifically designed to increase cervical cancer screening rates in women with a **sensory disability** (deafness) found a large but imprecise effect on screening rates (RR 23, 95% CI, 3.18 to 166).

No study of **colorectal cancer screening** or **screening for hypertension** found any interventions to be associated with improved receipt of screening among people with **cognitive/intellectual/developmental disabilities** or **serious mental illness**. One RCT on an intervention to improve general health, with outcomes related to **weight loss to reduce obesity-related morbidity**, found that people with **cognitive/intellectual/developmental disabilities** who received the intervention were more likely to have a weight management plan than those with usual care, although the finding was not statistically significant. Evidence on interventions to improve the receipt of other clinical preventive services (**screening for depression risk in adults, screening for prediabetes/type 2 diabetes, and interventions for falls prevention**) was limited to one study for each preventive service, with no clear effect of the interventions for any preventive service.

## Strengths and Limitations

Notable strengths of this systematic review included the use of a broad search strategy with terms for disability based on health conditions and aspects of functional ability, and the inclusion of a set of clinical presentative services with evidenced-based recommendations from the USPSTF, representing various general types of services, a breadth of health conditions and circumstances, and characterized by a variety of different functional requirements and potential barriers for participation for people with different types of disability. Recognizing that the receipt of different clinical preventive services by people with different types of disability may be influenced by different barriers/facilitators and/or influenced differentially by particular

barriers/facilitators, we organized and presented the findings of this review for individual clinical preventive services, according to individual types of disability.

Limitations of this review may have resulted from processes and decisions we made in applying standard methods for systematic reviews to this specific topic and Key Questions, as described in the full report. The most notable limitation of the body of evidence was the lack of relevant studies for most of the clinical preventive services and types of disability for the descriptive question on reported barriers and facilitators (Key Question 1), and especially the questions related to the effectiveness of interventions (Key Questions 2-4). Because of the limited available data and the high methodological/clinical heterogeneity of the studies, we did not assign strength of evidence ratings or conduct meta-analyses.

## **Implications and Conclusions**

The findings of this systematic review did not provide clear or sufficient evidence to support any specific clinical or policy decisions regarding the effectiveness of interventions to improve the receipt of clinical preventive services for people with disabilities. We found limited evidence on barriers and facilitators to the receipt of most clinical preventive services among people with disabilities, and especially limited evidence on interventions to improve the receipt of those preventive services. Most evidence was for two preventive services – breast cancer screening and cervical cancer screening – consistent with previous studies on disparities in the receipt of preventive services among people with disabilities, the preponderance of which are also on breast and cervical cancer screening. The lack of studies for most preventive services and types of disability underscores the need for research to address the substantial gaps in the evidence.

# Chapter 1. Background and Purpose

## Background

People with disabilities<sup>a</sup> are a substantial portion of the population. Data from the U.S. Census Bureau indicate that 30.3 percent of the adult civilian population of the United States (72.7 million people) had some form of disability in 2014, and 20.0 percent (47.9 million people) had a severe disability.<sup>1</sup> The prevalence of specific measures of disability among adults in the United States was 11.7 percent for seeing/hearing/speaking; 16.2 percent for walking/using stairs; 12.4 percent for various selected physical tasks (e.g., lifting, standing, pushing/pulling); 7.4 percent for limitation in activities of daily living (ADLs); 11.5 percent for limitation in instrumental activities of daily living (IADLs); and 12.5 percent for mental disability (including learning disability, intellectual disability and developmental disability, as well as dementia and other mental/emotional conditions).<sup>1</sup> Furthermore, 10.2 percent of the adult population had a disability in two of three general domains (communicative, physical, and mental) and 3.8 percent had a disability in all three domains.<sup>1</sup> People with disabilities are more likely than those without disabilities to be unemployed, have lower earnings, live in poverty, have lower levels of educational attainment, and be without health insurance.<sup>1-3</sup> Data from the 2020 Behavioral Risk Factor Surveillance System (BRFSS) indicates people with disabilities are also more likely to have depression (42% vs. 12%), diabetes (16% vs. 7%), obesity (40% vs. 29%), heart disease (10% vs. 4%), and to smoke (24% vs. 12%).<sup>3</sup>

Although it has long been recognized that people with disabilities have at least the same need for health maintenance and preventive services as the general population,<sup>4,7</sup> long-standing disparities in the receipt of various clinical preventive services persist among people with disabilities. Cancer screening is the most commonly studied general category of clinical preventive services in people with disabilities, especially screening for breast, cervical, and colorectal cancers.<sup>8-11</sup> Studies have been mostly consistent in finding that people with various disabilities are less likely to receive indicated screening for breast and cervical cancer.<sup>12-16</sup> For example, both the 2020 BRFSS and the 2021 National Health Interview Survey (NHIS) found women with any disability less likely to have received a mammogram in the past 2 years compared with women with no disability (BRFSS: 73.5% vs. 80.4%, respectively; NHIS: 65.3% vs. 77.9%, respectively) and less likely to be up-to-date on cervical cancer screening (BRFSS: 77.9% vs. 84.2%, respectively; NHIS: 62.4% vs. 74.5%, respectively).<sup>3,17</sup> Studies on disparities in colorectal cancer screening have been mixed; some finding people with disabilities to be slightly more likely to be up-to-date compared with people without a disability,<sup>3,17</sup> and others finding people with disabilities less likely to be up-to-date.<sup>18,19</sup> Although less well studied than the afore-mentioned three cancer screenings, other clinical preventive services for which evidence generally shows a disparity in care among people with disabilities include: screening for hypercholesterolemia, body mass index, hypertension, tobacco/nicotine use, alcohol misuse, opioid abuse, and risk for sexually transmitted infections; nutrition and exercise counselling; and receipt of various vaccinations.<sup>11,20-27</sup>

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<sup>a</sup> We recognize that individuals or groups with different disabilities have preferences about the terms that are used to refer to them. This may include choices to be referred to in person-first language or identity-first language. We use a mix of person-first and identity-first language in this report. We use the term “D/deaf” to encompass people who identify as culturally Deaf and part of the Deaf community and those who do not. Resources: <https://apastyle.apa.org/style-grammar-guidelines/bias-free-language/disability>; <https://www.apa.org/about/apa/equity-diversity-inclusion/language-guidelines> (APA, 2020).



## Chapter 1. Background and Purpose

Various barriers to the receipt of clinical preventive services for people with disabilities have been identified, including: physical environmental barriers; attitudes, behaviors, and/or lack of knowledge on the part of healthcare providers; communication failures between healthcare professionals and patients; transportation barriers; and financial barriers.<sup>8,9,28</sup> While many of these barriers may be common to different types of disability (e.g., mobility, cognitive/developmental, visual, hearing), studies have assessed barriers related to particular types of disability and/or particular types of preventive service.<sup>10,29-36</sup> In addition, studies have found disparities in the receipt of preventive services to vary according to type and severity of disability.<sup>21,37,38</sup> This suggests that the receipt of different clinical preventive services by people with different types or severity of disability may be influenced differentially by particular barriers – a view that is consistent with the integrative model of human functioning and disability represented by the International Classification of Functioning, Disability, and Health (ICF)<sup>b</sup> of the World Health Organization (WHO).<sup>39,40</sup>

A challenge for policymakers and healthcare organizations is how to best address these disparities to facilitate uptake of recommended clinical preventive services among people with disabilities. The challenge arises from and is complicated by many factors, including: the various definitions and ways of measuring disability;<sup>41-45</sup> the diverse nature of different types of disability (e.g., mobility, sensory, cognitive/developmental), with each presenting different types of potential challenges for the receipt of preventive services; the variety of different preventive services, each with different functional requirements and potential barriers for participation; and the complex interactions of an individual's functional abilities with various environmental factors (physical, social, attitudinal).<sup>39</sup>

### Purpose and Scope of this Review

The purpose of this Systematic Review is: (1) to document and summarize identified primary barriers and facilitators to the receipt of clinical preventive services among people with disabilities; and (2) to identify and synthesize the literature on the effectiveness of interventions to improve the receipt of clinical preventive services among people with disabilities. The review is intended for the target audiences of policymakers, healthcare organizations, advocates for people with disabilities, and researchers, to help guide and inform efforts to address disparities in the receipt of clinical preventive services among people with disabilities. Agency for Healthcare Research and Quality (AHRQ) will be supporting a follow-on stakeholder meeting to discuss the findings of this review and develop recommendations for future research. AHRQ will be working collaboratively with other Federal agencies, particularly in partnership with the Federal government's primary disability research organization, the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), to accomplish these goals. AHRQ received Congressionally directed funding for this systematic review and the stakeholder meeting.

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<sup>b</sup> The ICF distinguishes body function from participation in life situations and views disability not as intrinsic to an individual, but as an outcome of the interaction between an individual's health conditions and environmental factors. Accordingly, a person would have a disability with regard to a particular preventive service if the interaction of their functional ability and environmental factors restricted their participation in that service. Environmental factors may be physical (e.g., accessibility of facilities), social (e.g., communication, health system policies or procedures) or attitudinal (e.g., healthcare provider knowledge or awareness). The ICF model also includes personal factors that can affect participation (e.g., knowledge and self-efficacy).

# Chapter 2. Methods Summary

This Systematic Review follows methods of the *Agency for Healthcare Research and Quality (AHRQ) Methods Guide for Effectiveness and Comparative Effectiveness Reviews* (hereafter the “AHRQ Methods Guide”).<sup>46</sup> Methods were determined a priori and a protocol was developed through a standard AHRQ process that included collaboration with Federal partners, Key Informants, and Technical Expert Panel. The protocol was registered on the PROSPERO systematic reviews registry (CRD42023479105) and published on AHRQ’s website:

[https://effectivehealthcare.ahrq.gov/products/people-with-disabilities/protocol#field\\_report\\_title\\_7](https://effectivehealthcare.ahrq.gov/products/people-with-disabilities/protocol#field_report_title_7)

## Key Questions

The following questions were included with a scope of work issued by AHRQ and revised with input from Federal partners, Key Informants, and Technical Expert Panel.

**Key Question 1.** What are the primary barriers and facilitators<sup>c</sup> to the receipt of clinical preventive services among people with disabilities?

- a. How do these barriers/facilitators vary according to preventive service?
- b. How do these barriers/facilitators vary according to type and/or severity of disability?
- c. How do these barriers/facilitators vary according to characteristics such as: gender, race/ethnicity, economic status, LGBTQ+ status, or geographic location?

**Key Question 2.** What is the effectiveness of interventions to improve the receipt of clinical preventive services among people with disabilities?

- a. How does the effectiveness vary according to preventive service?
- b. How does the effectiveness vary according to type and/or severity of disability?
- c. How does the effectiveness vary according to characteristics such as: gender, race/ethnicity, economic status, LGBTQ+ status, or geographic location?

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<sup>c</sup> Categories of barriers and facilitators may include but are not limited to:

- Environment-level (e.g., transportation; need/availability of guardian or caregiver)
- Person-level (e.g., fear; discomfort; functional ability; self-efficacy)
- Provider-level (e.g., disability knowledge/assumptions; bias or ableism; communication skills)
- Health system (e.g., insurance; patient functionality information in records; procedural accommodations, such as visit length and clinician reimbursement)
- Accessibility of health facilities (e.g., physical facility; equipment; sensory environment; telehealth)
- Accessible communication (e.g., within facility; from outside of facility)
- Policy-level (e.g., Federal or State laws)

## Chapter 2. Methods Summary

**Key Question 3.** What are the characteristics and/or components of interventions that contribute to their effectiveness (or lack of effectiveness) in mitigating barriers to the receipt of clinical preventive services among people with disabilities?

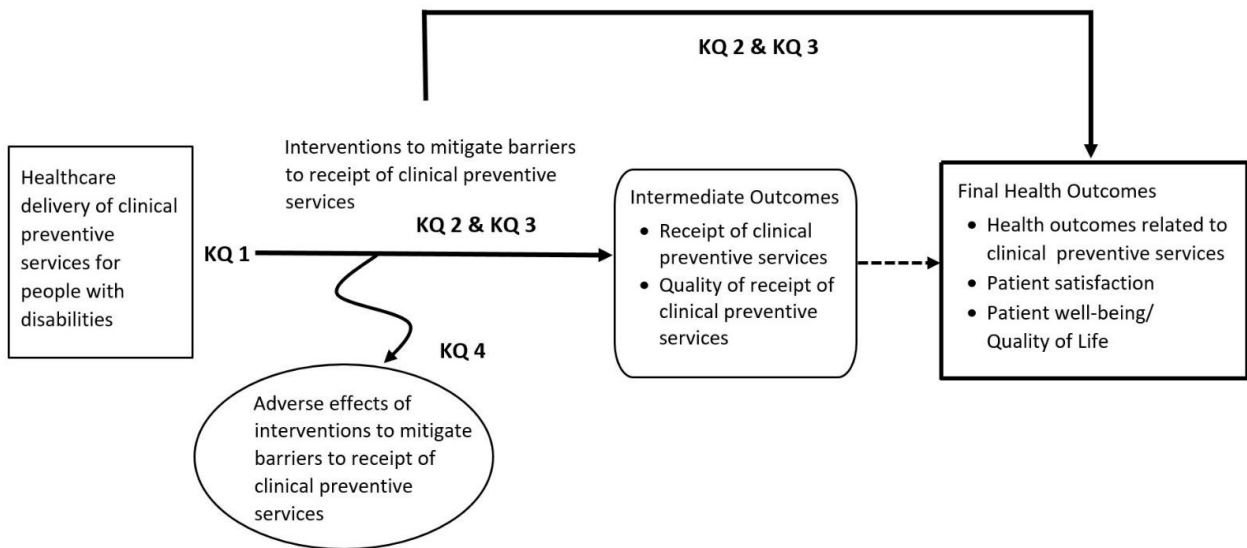
- How does the effectiveness vary according to preventive service?
- How does the effectiveness vary according to type and/or severity of disability?
- How does the effectiveness vary according to characteristics such as: gender, race/ethnicity, economic status, LGBTQ+ status, or geographic location?

**Key Question 4.** What are the harms of intervention programs to mitigate barriers to the receipt of clinical preventive services among people with disabilities?

- How do the harms vary according to preventive service?
- How do the harms vary according to type and/or severity of disability?
- How do the harms vary according to characteristics such as: gender, race/ethnicity, economic status, LGBTQ+ status, or geographic location?

## Analytic Framework

Figure 1. Analytic framework<sup>a</sup>



Abbreviation: KQ = Key Question

<sup>a</sup> The analytic framework illustrates how the populations, interventions, and outcomes relate to the Key Questions for the review.

## PICOTS

The PICOTS (population, interventions, comparators, outcomes, timing, setting) framework helps operationalize Key Questions and definitions into criteria for searches and inclusion/exclusion decisions. Table 1 describes the PICOTS used to help screen studies.

## Chapter 2. Methods Summary

**Table 1. PICOTS and corresponding inclusion and exclusion criteria**

Element	Include	Exclude
<b>Population</b>	<ul style="list-style-type: none"> <li>• People with disabilities (including: physical; cognitive/intellectual/developmental; sensory; serious psychiatric/mental illness)</li> <li>• Adults and children</li> <li>• Specific populations of interest:               <ul style="list-style-type: none"> <li>- Age</li> <li>- Gender</li> <li>- Race/ethnicity</li> <li>- Economic status</li> <li>- LGBTQ+ status</li> <li>- Geographic location (regional and urban/rural)</li> <li>- Immigration status</li> <li>- Incarcerated</li> <li>- Unhoused</li> <li>- Language spoken</li> <li>- Use of a guardian/proxy for healthcare decisions</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Studies that do not include people with disabilities or do not report outcomes according to disability status</li> </ul>
<b>Intervention</b>	<ul style="list-style-type: none"> <li>• Interventions to mitigate barriers and/or improve the receipt of clinical preventive services among people with disabilities (e.g., modification in policies, practices, and procedures; effective communication; the physical accessibility of facilities; educational/training programs for healthcare providers)</li> <li>• Characteristics/components of interventions (KQ3) may include elements such as: staffing, funding, facilities, equipment, training</li> <li>• Clinical preventive services listed in Appendix A, Table A-2, derived from USPSTF Grade A and Grade B recommendations:               <ul style="list-style-type: none"> <li>- Screening (anxiety disorders, breast cancer, cervical cancer, colorectal cancer, depression, HIV infection, hypertension, intimate partner violence, osteoporosis, diabetes, unhealth drug or alcohol use)</li> <li>- Interventions or behavioral counseling (breastfeeding, falls prevention, perinatal depression, tobacco use/cessation, weight loss, healthy diet and physical activity, sexually transmitted infections)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Interventions that do not address barriers to receipt of clinical preventive services for people with disabilities</li> <li>• Preventive services not listed in Appendix A, Table A-2.</li> </ul>
<b>Comparator</b>	<ul style="list-style-type: none"> <li>• Another intervention</li> <li>• No intervention</li> <li>• No comparator (when adequate comparative studies are lacking)</li> </ul>	
<b>Outcome</b>	<ul style="list-style-type: none"> <li>• Receipt of clinical preventive service</li> <li>• Quality of receipt of clinical preventive service</li> <li>• Health outcomes related to clinical preventive service</li> <li>• Patient satisfaction</li> <li>• Patient well-being</li> <li>• Harms of the intervention program</li> </ul>	<ul style="list-style-type: none"> <li>• Cost-effectiveness</li> <li>• Outcomes not related to included clinical preventive services listed in Appendix A, Table A-2.</li> </ul>
<b>Timing</b>	<ul style="list-style-type: none"> <li>• All</li> </ul>	
<b>Setting</b>	<ul style="list-style-type: none"> <li>• Primary care outpatient clinics</li> <li>• Community health clinics</li> <li>• Settings referable from primary care settings</li> <li>• Emergency departments</li> <li>• Other settings (e.g., home, residence, mobile care units)</li> <li>• United States or countries with a "very high" United Nations Human Development Index</li> </ul>	

Abbreviations: KQ = Key Question; LGBTQ+ = Lesbian Gay Bisexual Transgender Queer/questioning plus/others; PICOTS = population, interventions, comparators, outcomes, timing, setting; USPSTF = United States Preventive Services Task Force

# Systematic Review Procedures

## Literature Search Strategy

A research librarian, with expertise conducting searches for systematic reviews, developed the search strategy, which was reviewed by the Technical Expert Panel and a second research librarian. We searched Ovid<sup>®</sup>, MEDLINE<sup>®</sup>, PsycINFO<sup>®</sup>, Embase<sup>®</sup>, the Cochrane Central Register of Controlled Trials, and EBSCO CINAHL Plus from 1990, the year of the passage of the Americans with Disabilities Act (ADA), through November, 2023. The full search strategies are included in Appendix A. Our database search strategy was informed by an earlier search strategy developed by Walsh et al,<sup>47</sup> which used the International Classification of Functioning, Disability, and Health (ICF) concept of disability, and was refined with additional MeSH terms and keywords to meet the needs of this review. To identify literature on specific preventive services, we reviewed the published search strategies from relevant United States Preventive Services Task Force (USPSTF) reports and refined our searches accordingly.<sup>48</sup> Reference lists of included studies and relevant systematic reviews were searched for includable literature. Searches will be updated while the draft report is being reviewed and open for public commentary; we will consider suggestions received from reviewers and in public comments on the draft report.

## Criteria for Inclusion/Exclusion of Studies in the Review

Criteria for determining the inclusion and exclusion of abstracts were established *a priori* and in accordance with the AHRQ Methods Guide.<sup>46</sup> These criteria were based on the Key Questions and the PICOTS framework presented in Table 1, above, and are elaborated with regard to included study designs below. For all studies, two reviewers independently screened abstracts and full-text articles. All abstracts excluded by one team member were reviewed by a second team member to determine inclusion or exclusion. Abstracts deemed appropriate for inclusion by at least one reviewer were retrieved for review of the full-text article. Each full-text article was independently reviewed for eligibility by two team members. Disagreements regarding inclusion/exclusion at the full-text level were resolved by discussion and consensus among team members. Team members were not involved in decisions about inclusion for studies on which they were authors. We used DistillerSR software (*DistillerSR*. Version 2.35. DistillerSR Inc.; 2022) to assist with abstract and full-text review for inclusion/exclusion decisions and tracking. A record of studies excluded at the full-text level with reasons for exclusion was maintained and is included in Appendix D.

The following criteria, related to study design and reporting, were also used to determine inclusion and exclusion of studies:

**Key Question 1.** We considered for inclusion: trials, observational studies, surveys, descriptive studies, and qualitative studies (e.g., focus groups or formal key informant interviews) that were designed to describe and/or assess barriers to and/or facilitators of the receipt of clinical preventive services for people with disabilities. Previous systematic reviews have characterized barriers/facilitators for healthcare in general among people with disabilities; the focus of this review was on barriers/facilitators related to the receipt of clinical preventive services. Studies that were not designed specifically to assess barriers/facilitators to the receipt of clinical preventive services were excluded. We considered for inclusion studies that described

## Chapter 2. Methods Summary

barriers/facilitators as experienced or perceived by patients, caregivers, clinicians or other healthcare workers, administrators, or others whose roles are relevant to the receipt of clinical preventive services for people with disabilities. We included relevant studies of individuals with multiple co-occurring types of disability (e.g., physical and cognitive). We included studies of various different types of disability, if the study reported barriers/facilitators as related to the specific type of disability and/or made clear that reported barriers/facilitators applied to all of the included types of disability. We included studies of multiple clinical preventive services, if the study reported barriers/facilitators as related to the specific type of preventive service and/or made clear that reported barriers/facilitators applied to all of the included preventive services.

**Key Questions 2, 3, and 4.** We considered for inclusion trials and observational studies (e.g., cohorts or before-after designs) of interventions to improve the receipt of clinical preventive services among people with disabilities. As indicated in Table 1, interventions of interest included a variety of types (e.g., behavioral/educational, modification of physical facilities/equipment, changes in policy/practices) addressing a variety of targets (e.g., patients, clinicians, physical facilities, healthcare organizations, communities). Our initial inclusion criteria were limited to comparative studies (i.e., an intervention compared with another intervention or with no intervention), and excluded studies with data from only one point in time. However, after completion of the first review (single reviewer) of abstracts and full-text papers, we had identified a relatively small number of comparative studies for inclusion; and, therefore, we submitted to AHRQ a formal amendment to the protocol. Following the amended protocol, we used a best evidence approach for the second review (dual review) of abstracts and full-text papers, in which we considered noncomparative studies or studies with data from only one time-point (e.g., diagnostic accuracy) when adequate comparative studies were lacking. Included studies may or may not have defined specific barriers that an intervention was intended to mitigate. Interventions that also addressed factors other than clinical preventive services were considered for inclusion, provided that the study assessed and reported on the effect of the intervention on included outcomes related to included clinical preventive services. We excluded descriptive studies with no outcomes data.

For all Key Questions, we considered for inclusion recent systematic reviews that addressed the Key Questions and were rated high quality (e.g., using AMSTAR 2).<sup>49</sup> We excluded commentaries, letters, narrative reviews, conference abstracts, and articles that described interventions and/or barriers/facilitators but were not the actual reports of the relevant studies. Inclusion was restricted to English-language articles.

**Clinical Preventive Services.** The list of clinical preventive services included in the systematic review (Appendix A, Table A-2) was developed with input from the Technical Expert Panel, the AHRQ Task Order Officer, and content experts on the Evidence-based Practice Center (EPC) team. Each included preventive service has a Grade A or Grade B recommendation from the USPSTF as of September 27, 2023,<sup>48</sup> and was considered to be applicable and relevant to a large segment of the general population, including people with disabilities. To be considered for inclusion, a study must have addressed and/or measured an approach to providing the preventive service that is endorsed by the USPSTF Grade A or Grade B recommendation. For example, the USPSTF Grade B recommendation for breast cancer screening applies to screening mammography, but not to breast self-exam; and the USPSTF Grade B recommendation for

## Chapter 2. Methods Summary

interventions for falls prevention in community-dwelling older adults applies to exercise interventions, but not to multifactorial interventions.

In defining the scope of the review, these preventive services were considered to be of high priority for inclusion by Technical Expert Panel members and content experts. The list includes various general types of preventive services (screening, intervention, counselling), representing a breadth of health conditions and circumstances. The included preventive services are also characterized by a variety of different functional requirements and potential barriers for participation, with relevance to people with different types of disability (e.g., mobility, sensory, cognitive/developmental).

### Data Extraction

We developed data abstraction tables using Excel software after completion of the full-text review for inclusion. Data from included studies were abstracted into Excel data tables by one team member, and then translated into summary tables. A second reviewer spot checked the data abstraction for accuracy. Team members were not involved in data abstraction for studies on which they were authors.

For all studies, we abstracted general data, including: study design, year of publication, setting, country, sample size, patient characteristics (e.g., age, gender, race, economic status), type(s) of disability (e.g., physical, cognitive/intellectual/developmental, sensory, serious psychiatric/mental illness), definition/measure of disability, if reported (e.g., activities of daily living [ADLs], instrumental activities of daily living [IADLs], Behavioral Risk Factor Surveillance System [BRFSS], National Health Interview Survey [NHIS], functional measures), severity of disability, type(s) of clinical preventive service, and source of funding.

For Key Question 1, we also abstracted data on the source of information on barriers/facilitators (e.g., patient, caregiver, family member, clinician, other healthcare worker, administrator), the reported barriers and/or facilitators, and the general category of each reported barrier/facilitator (e.g., environment-level, person-level, provider-level). In addition, we consolidated conceptually similar barriers/facilitators within overarching themes in the Excel tables (e.g., “transportation” to include various barriers/facilitators related principally to transportation).

For Key Questions 2, 3, and 4, we also abstracted data on intervention characteristics (e.g., type of intervention, target of intervention, specific characteristic/components of intervention, mode of delivery, duration or frequency), reported outcomes and results, effectiveness of specific components of an intervention, if reported (Key Question 3), and harms of an intervention (Key Question 4).

### Assessment of Individual Studies

We assessed risk of bias (internal validity) for controlled trials and nonrandomized studies of interventions (NRSIs) – mostly observational studies – using study design-specific criteria, as recommended in the chapter, “Assessing the Risk of Bias of Individual Studies When Comparing Medical Interventions” in the AHRQ Methods Guide.<sup>46</sup> Randomized controlled trials were evaluated using Cochrane risk of bias criteria,<sup>50</sup> and observational studies were evaluated using criteria developed by the USPSTF.<sup>51</sup> To evaluate the general quality of the qualitative studies included for Key Question 1, we used the screening questions and qualitative category criteria of the Mixed Methods Appraisal Tool (MMAT), Version 2018,<sup>52</sup> with guidance from an expert on the team (Appendix A). Cross-sectional studies were not assessed for risk of bias.

## Chapter 2. Methods Summary

Each study was independently reviewed for risk of bias or general quality (Key Question 1) by two team members. Team members were not involved in quality or risk of bias assessments for studies on which they were authors. Any disagreements were resolved through discussion and consensus. Based on the risk of bias assessment, studies were rated as having “low,” “moderate,” or “high” risk of bias. For qualitative studies, general quality was rated as “good,” “fair,” or “poor.”

### Data Synthesis

Data synthesis differed between the Key Questions. A brief description of the synthesis methods is included here and illustrated in more detail in the Results sections for each Key Question. For each question, we constructed tables with the relevant data from included studies (as described in the section on data abstraction, above). For each Key Question, we also constructed summary tables of the body of evidence, which highlight the main findings for each clinical preventive service, according to each specific type of disability (e.g., physical, cognitive/intellectual/developmental, sensory, serious psychiatric/mental illness).

For Key Question 1, for each clinical preventive service for which evidence was identified, the general, predetermined categories of reported barriers and facilitators (e.g., environment-level, person-level, provider-level, etc.) were summarized in tables, according to the type(s) of disability for which the category of barrier/facilitator was reported in a study. Additionally, for each type of preventive service, detailed lists of the specific reported barriers and facilitators for each type of disability were synthesized and presented in tables, clustered within each general category of barrier/facilitator (e.g., environment-level, person-level, provider-level, etc.). The findings were also summarized narratively for each clinical preventive service and type of disability.

For Key Question 2, for each clinical preventive service for which evidence was identified, we constructed a summary table, in which all included studies are presented according to the type(s) of disability studied, and in which the basic nature of the interventions and the main results are presented. The findings were also summarized narratively for each clinical preventive service and type of disability, with detailed descriptions and discussions of the studies and their findings. We did not attempt to assign strength of evidence ratings, due to the high methodological and clinical heterogeneity of the intervention strategies in the included studies, and out of concern that indirect comparisons between various heterogeneous interventions would not meaningfully address the questions and would lead to unreliable and potentially misleading conclusions. For the same reason – the high methodological and clinical heterogeneity of the intervention strategies in the included studies – we did not conduct quantitative pooled syntheses (meta-analyses).



## Chapter 3. Results

### 3.1 Included Studies

A total of 11,198 abstracts from electronic database searches and reference lists were reviewed; 739 papers were identified from the search and reference lists for full-text review, of which 671 articles were excluded (Appendix B). We included 68 studies for all Key Questions. For Key Question 1, we included 54 studies with qualitative or mixed methods designs (e.g., surveys, interviews, focus groups). For Key Question 2, 16 studies were included (7 randomized controlled trials [RCTs], 7 observational/nonrandomized studies of interventions [NRSIs], and 2 cross-sectional studies). Two included studies related to Key Question 3, and one study related to Key Question 4. A list of included studies can be found in Appendix C, and a table with included studies according to the clinical preventive service(s) and type(s) of disability addressed in Key Question 1 can be found in Appendix G. A list of excluded studies with reason for exclusion are in Appendix D. Data abstraction tables are in Appendix E. Risk of bias or quality assessment tables are in Appendix F.

## 3.2. Results, Key Question 1. Primary barriers and facilitators to the receipt of clinical preventive services

### 3.2 Key Question 1. What are the primary barriers and facilitators to the receipt of clinical preventive services among people with disabilities?

#### 3.2.1 Key Points

- Fifty-four studies reported on barriers and/or facilitators to the receipt of clinical preventive services among people with disabilities. Studies were related to 10 of the 20 clinical preventive services included in the review: screening for anxiety disorder in adults (n=1); breast cancer screening (n=36); cervical cancer screening (n=19); colorectal cancer screening (n=6); screening for depression risk in adults (n=3); screening for HIV infection (n=1); screening for unhealthy alcohol use (n=2); interventions for falls prevention in community-dwelling older adults (n=1); counselling for healthy diet and physical activity for cardiovascular disease (CVD) prevention (n=1); and behavioral counselling to prevent sexually transmitted infections (n=3).
- By far, the largest number of studies were related to barriers/facilitators for the receipt of **breast cancer screening or cervical cancer screening**. The studies on these two preventive services pertained to people with disabilities of all general types (physical; cognitive/intellectual/developmental; sensory; serious psychiatric/mental illness), with the majority of studies pertaining to people with physical disabilities (breast cancer screening, n=18; cervical cancer screening, n=8) or cognitive/intellectual/developmental disabilities (breast cancer screening, n=15; cervical cancer screening, n=7). (See Appendix G, Table G-1 for details).
- For **breast cancer screening**, most categories of barriers/facilitators (environment-level, person-level, provider-level, healthcare system-level, accessibility of healthcare facility, accessible communication) were reported for all types of disability, with the exception that policy-level barriers were reported only for people with cognitive/intellectual/developmental disability and serious mental illness.
- For **breast cancer screening among women with physical disabilities**, most reported barriers were at the person level (e.g., difficulty standing still, fear and/or embarrassment), the provider level (e.g., ableism, lack of knowledge about people with disabilities), and the level of the healthcare system (e.g., difficulty booking/attending appointments). Most reported facilitators were at the provider level (e.g., knowledge about people with disabilities).
- For **breast cancer screening among women with cognitive/intellectual/developmental disabilities**, most reported barriers were at the environment level (e.g., family/caregiver feeling overwhelmed, transportation), the person level (e.g., fear and/or embarrassment, inability to give informed consent), and the provider level (e.g., lack of knowledge about people with disabilities, not assessing the need for a decision-making delegate). Most reported facilitators were at the person level (e.g., feeling in control, having coping strategies), the provider level (e.g., allowing preparatory visits, providing explanations before the procedure), and the level of the healthcare system (e.g., extra time for appointments).
- For **cervical cancer screening among women with physical disabilities**, most reported barriers were at the person level (e.g., feeling dependent on others, pain or discomfort with screening) and the provider level (e.g., negative attitude/ableism, not listening to the

### 3.2. Results, Key Question 1. Primary barriers and facilitators to the receipt of clinical preventive services

person with disabilities). Most reported facilitators were at the provider level (e.g., assistance with dressing, knowledge about people with disabilities).

- For **cervical cancer screening among women with cognitive/intellectual/developmental disabilities**, most reported barriers were at the person level (e.g., inability to give informed consent, not understanding the screening process) and the provider level (e.g., ableism, misconceptions about sexual activity and need for screening). Most reported facilitators were at the provider level (e.g., adjusting procedures to accommodate the patient, providing an explanation before the procedure).
- The studies on **colorectal cancer screening** (n=6) pertained to people with physical disabilities (n=4) or people with serious mental illness (n=2). Most categories of barriers/facilitators (environment-level, person-level, provider-level, healthcare system-level, accessibility of healthcare facility) were reported for both types of disability; no barriers or facilitators within the categories of accessible communication or policy were reported for either type of disability.
- Studies on **screening for depression risk** in adults (n=3) pertained to people with cognitive/intellectual/developmental disabilities and people with sensory disabilities. Studies on **behavioral counselling to prevent sexually transmitted infections** (n=3) pertained to people with physical disabilities and people with serious mental illness. Studies on screening for unhealthy alcohol use (n=2) pertained only to people with cognitive/intellectual/developmental disabilities. For each of the other preventive services, only one study was identified, each study related to only one type of disability: **screening for HIV infection** (people with sensory disabilities); **interventions for falls prevention in community-dwelling older adults** (people with cognitive disability); and **counselling for healthy diet and physical activity for CVD prevention** (people with serious mental illness). (See Appendix G, Table G-1 for details).

#### 3.2.2 Summary of Findings

The findings for Key Question 1 are summarized and presented below for each of the 10 clinical preventive services for which we identified studies. For each preventive service, findings are presented by each general type of disability (physical, cognitive/intellectual/developmental, sensory, serious psychiatric/mental illness), with specific reported barriers and facilitators classified by general category (environment-level, person-level, provider-level, healthcare system-level, accessibility of healthcare facility, accessible communication, policy-level).

##### 3.2.2.1 Anxiety Disorder Screening in Adults

We identified one study that reported on barriers and facilitators to the receipt of screening for anxiety disorder among adults with disabilities.<sup>53</sup> The study used focus groups and interviews to understand barriers and facilitators to the implementation of clinical practice guidelines for depression and anxiety in patients with dementia or Parkinson's disease, and addressed the breadth of clinical practice guidelines, including diagnosis and treatment/management. Because the focus group/interview questions combined dementia and Parkinson's disease – and did not report on physical disabilities related to Parkinson's disease – we have categorized the relevant study population to be people with cognitive/intellectual/developmental disabilities. The general quality of the study was assessed as good.

Most participants were physicians (n=33), representing various relevant specialties (family practitioners, geriatricians, geriatric psychiatrists, cognitive neurology, and movement disorders);

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the study also included patients with Parkinson’s disease or their caregivers (n=7). Although most of the reported barriers/facilitators related to treatment/management or to other aspects of diagnosis, some barriers and facilitators related directly or indirectly to screening itself. All of the barriers and facilitators related to screening were in the provider-level category and appeared to be reported by physicians. The reported barriers included: provider being unprepared, misconceptions about scope of practice, and lack of knowledge about people with disabilities. The reported facilitators included: use of screening tools and comprehensive knowledge of the procedure (Table 2).

**Table 2. Screening for anxiety disorder in adults – cognitive/intellectual/developmental disability: barriers and facilitators**

Provider-Level Barriers	Provider-Level Facilitators
<ul style="list-style-type: none"> <li>• Provider being unprepared</li> <li>• Misconceptions about scope of practice</li> <li>• Lack of knowledge about people with disabilities</li> </ul>	<ul style="list-style-type: none"> <li>• Use of screening tools</li> <li>• Comprehensive knowledge of procedure, from screening to diagnosis</li> </ul>

#### 3.2.2.2 Breast Cancer Screening

We identified 36 studies that reported on barriers and/or facilitators to the receipt of breast cancer screening for people with disabilities.<sup>54-89</sup> Studies included people with physical disabilities (n=18), cognitive/intellectual/developmental disabilities (n=15), sensory disabilities (n=4), serious mental illness (n=6), and multiple co-occurring disabilities (n=2). Studies reported barriers/facilitators within all of the various general categories, including: environment-level, person-level, provider-level, healthcare system, accessibility of healthcare facilities, accessible communication, and policy-level (Tables 3 and 4, below). Studies used surveys (n=10) or a variety of qualitative methods, such as interviews or focus groups (n=27), to elicit information about barriers and/or facilitators from people with disabilities (n=29), caregivers (n=6), clinicians (n=5), or others (n=2). The general quality of studies was assessed as good (n=19) to fair (n=16) for most studies, and one study rated as poor, with the most common limitations related to unclear inclusion criteria, unclear reporting of response rate and missing data, and not using validated instruments in survey studies. Specific barriers and facilitators are reported for each general type of disability in the following sections (3.2.2.2.1 – 3.2.2.2.5).

**Table 3. Summary of barriers for breast cancer screening**

Categories of Barriers	Physical	Cognitive/Intellectual/Developmental	Sensory	Serious Mental Illness	Multiple Disabilities
Environment-level	✓	✓	✓	✓	--
Person-level	✓	✓	✓	✓	--
Provider-level	✓	✓	✓	✓	--
Health system	✓	✓	✓	✓	✓
Accessibility of healthcare facilities	✓	✓	✓	✓	✓
Accessible communication	✓	✓	✓	--	--
Policy-level	--	✓	--	✓	--

✓ = denotes one or more studies in this category

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**Table 4. Summary of facilitators for breast cancer screening**

Category	Physical	Cognitive/Intellectual/Developmental	Sensory	Serious Mental Illness	Multiple Disabilities
Environment-level	✓	✓	✓	✓	--
Person-level	✓	✓	--	✓	--
Provider-level	✓	✓	✓	✓	✓
Health system	✓	✓	✓	✓	--
Accessibility of healthcare facilities	✓	✓	--	✓	✓
Accessible communication	✓	✓	--	--	--
Policy-level	--	--	--	--	--

✓ = denotes one or more studies in this category

#### 3.2.2.2.1 Physical Disability

We identified 18 studies that reported on barriers and/or facilitators to the receipt of breast cancer screening for people with physical disabilities.<sup>56,57,59,60,64-66,70-72,74,77-80,83,87,88</sup> Studies reported barriers/facilitators within various general categories, including: environment-level, person-level, provider-level, healthcare system, accessibility of healthcare facilities, and accessible communication. Specific reported barriers are presented in Table 5, including: inaccessible mammography machine;<sup>57,59,70,71,74,77-80,88</sup> inaccessible healthcare facility;<sup>57,60,70,71,77,78,87,88</sup> person with disability believing that screening is not necessary;<sup>64,70,74,78</sup> negative attitude from provider;<sup>56,65,70,78,87</sup> transportation issues;<sup>57,65,70,71,78,80</sup> and treatment fatigue from disability/other comorbidities.<sup>65,78,83,87</sup> Specific reported facilitators are also presented in Table 5, including: accessible mammography machine;<sup>77,78,88</sup> accessible healthcare facility;<sup>59,66,72,77,79</sup> and provider being educated or have knowledge about treating people with disability.<sup>57,79</sup>

**Table 5. Breast cancer screening – physical disability: barriers and facilitators**

Screening Category	Barriers	Facilitators
Environment-level	<ul style="list-style-type: none"> <li>Lacking support/advocacy</li> <li>Transportation issue</li> </ul>	<ul style="list-style-type: none"> <li>Reliable transportation</li> <li>Supportive family/caregiver</li> </ul>
Person-level	<ul style="list-style-type: none"> <li>Difficulty staying still</li> <li>Distrust of the healthcare system</li> <li>Fear of screening because of family history of breast cancer</li> <li>Fear and/or embarrassment</li> <li>Feeling vulnerable</li> <li>Lacking health education</li> <li>Not understanding the screening process</li> <li>Pain or discomfort with screening</li> <li>PwD believing screening not necessary</li> <li>PwD not informed about insurance coverage</li> <li>Treatment fatigue from disability/other comorbidities</li> </ul>	<ul style="list-style-type: none"> <li>PwD being health consciousness</li> <li>PwD feeling in control</li> <li>PwD understanding screening</li> </ul>

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Screening Category	Barriers	Facilitators
<b>Provider-level</b>	<ul style="list-style-type: none"> <li>• Lack of knowledge about PwD</li> <li>• Lack of provider recommendation</li> <li>• Lack of rapport with PwD</li> <li>• Negative attitude toward patient/ableism</li> <li>• No explanation before screening procedure</li> <li>• Not listening to/overlooking PwD</li> <li>• Provider being unprepared</li> <li>• Relying on provider to perform or order screening</li> </ul>	<ul style="list-style-type: none"> <li>• Education and/or knowledge about PwD</li> <li>• Explanation provided before screening procedure</li> <li>• Good rapport with provider</li> <li>• Listening to patients' needs</li> <li>• Provider adjusting screening procedures to accommodate patient's disability</li> <li>• Providing referrals</li> <li>• Understanding barriers</li> </ul>
<b>Healthcare system</b>	<ul style="list-style-type: none"> <li>• Difficulty with booking and attending appointments</li> <li>• Lack of primary care provider</li> <li>• Lacking insurance</li> <li>• No reminder to receive screening</li> <li>• Provider time constraints</li> </ul>	<ul style="list-style-type: none"> <li>• Care continuity</li> <li>• Reduction of cost to receive service</li> <li>• Reminder to receive screening</li> </ul>
<b>Accessibility of facilities</b>	<ul style="list-style-type: none"> <li>• Inaccessible facility</li> <li>• Inaccessible mammography equipment</li> <li>• Inaccessible mammography equipment</li> </ul>	<ul style="list-style-type: none"> <li>• Accessible facility</li> <li>• Accessible mammography equipment</li> </ul>
<b>Accessible communication</b>	<ul style="list-style-type: none"> <li>• Difficulty communicating with PwD</li> </ul>	<ul style="list-style-type: none"> <li>• Communication about disability needs</li> </ul>

Abbreviations: PwD = people with a disability/person with a disability

#### 3.2.2.2.2 Cognitive/Intellectual/Developmental Disability

We identified 15 studies that reported on barriers and/or facilitators to the receipt of breast cancer screening for people with cognitive, intellectual, or developmental disabilities.<sup>54,55,58,63,67-70,73,75,76,84-86,89</sup> Studies reported barriers/facilitators within various general categories, including: environment-level, person-level, provider-level, healthcare system, accessibility of healthcare facilities, accessible communication, and policy-level. Specific reported barriers are presented in Table 6, including: decision-making delegate's refusal;<sup>58,63,68-70,84</sup> difficulty communicating with a person with intellectual disability;<sup>54,63,84</sup> patients' fear and/or embarrassment;<sup>55,58,63,67,68,76</sup> inaccessible equipment;<sup>70,73,89</sup> inaccessible facility;<sup>54,68,70</sup> lack of provider recommendation;<sup>58,63,69,84</sup> lacking health education/promotion;<sup>54,68,75</sup> provider's negative attitude;<sup>54,58,63,70,73,86</sup> no explanation provided before the screening procedure;<sup>70,75,85,86,89</sup> patients not understanding the screening process;<sup>54,55,69,73</sup> and patient's pain or discomfort with screening.<sup>55,58,67,68,70,73,75,84,85,89</sup> Specific reported facilitators are also presented in Table 6, including: accessible communication methods;<sup>54,63,67,68,75,84,86</sup> people with disabilities having a supportive family/caregiver;<sup>54,68,70,73,75,84,85,89</sup> and people with disabilities being health conscious.<sup>75,86</sup>

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**Table 6. Breast cancer screening – cognitive/intellectual/developmental disability: barriers and facilitators**

Screening Category	Barriers	Facilitators
<b>Environment-level</b>	<ul style="list-style-type: none"> <li>Decision-making delegate's refusal</li> <li>Family/caregiver feeling overwhelmed</li> <li>Family/caregiver lacking health knowledge</li> <li>History of sexual assault</li> <li>Lacking support/advocacy</li> <li>Transportation issue</li> </ul>	<ul style="list-style-type: none"> <li>Reliable transportation</li> <li>Supportive family/caregiver</li> </ul>
<b>Person-level</b>	<ul style="list-style-type: none"> <li>Difficulty staying still for the procedure</li> <li>Distrusting of the healthcare system</li> <li>Fear and/or embarrassment</li> <li>Fear from having family history of breast cancer</li> <li>Feeling vulnerable</li> <li>Inability to give informed consent</li> <li>Lacking health education/promotion</li> <li>Not understanding screening process</li> <li>Pain or discomfort with screening</li> <li>PwD time constraints</li> <li>Treatment fatigue from disability/other comorbidities</li> </ul>	<ul style="list-style-type: none"> <li>Being health conscious</li> <li>Feeling in control</li> <li>Having coping strategies</li> <li>Having family history of breast cancer make PwD more receptive to screening</li> <li>Learning cancer symptoms</li> <li>Understanding screening</li> </ul>
<b>Provider-level</b>	<ul style="list-style-type: none"> <li>Lack of knowledge about PwD</li> <li>Lack of provider</li> <li>Lack of provider recommendation for screening</li> <li>Negative attitude toward patient/ableism</li> <li>No explanation before screening procedure</li> <li>Not assessing need for decision-making delegate</li> <li>Not listening to/overlooking PwD</li> </ul>	<ul style="list-style-type: none"> <li>Allowing preparatory visits</li> <li>Commitment to health promotion</li> <li>Explanation provided before screening procedure</li> <li>Good rapport with PwD</li> <li>Knowledge of individual patient and preferences</li> <li>Listening to PwD's needs and suggestions</li> <li>Measures to reduce pain during procedure</li> <li>Understanding barriers</li> </ul>
<b>Healthcare system</b>	<ul style="list-style-type: none"> <li>Appointment time constraints</li> <li>Lack of care coordination</li> <li>Lacking insurance</li> </ul>	<ul style="list-style-type: none"> <li>Allow sedation of PwD</li> <li>Allowing alternative procedure</li> <li>Bringing screening procedure to where PwD lives</li> <li>Care continuity</li> <li>Care coordination</li> <li>Extra appointment time</li> <li>Female provider</li> <li>Reduction of cost to receive service</li> <li>Reminder to receive screening</li> </ul>
<b>Accessibility of facilities</b>	<ul style="list-style-type: none"> <li>Inaccessible equipment</li> <li>Inaccessible facility</li> <li>Mobility issues</li> <li>Sensory environment</li> </ul>	<ul style="list-style-type: none"> <li>Closer location</li> </ul>
<b>Accessible communication</b>	<ul style="list-style-type: none"> <li>Difficulty communicating with person with intellectual disability</li> <li>Lack of communication about disability</li> <li>Lacking internet access</li> <li>Literacy issues</li> </ul>	<ul style="list-style-type: none"> <li>Accessible communication methods</li> </ul>
<b>Policy-level</b>	<ul style="list-style-type: none"> <li>Caregiver lacking decision-making authority</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>

Abbreviations: NA = not applicable; PwD = people with a disability/person with a disability

## 3.2. Results, Key Question 1. Primary barriers and facilitators to the receipt of clinical preventive services

### 3.2.2.2.3 Sensory Disability

We identified four studies that reported on barriers and/or facilitators to the receipt of breast cancer screening for people with sensory disabilities (visual impairment or deafness).<sup>66,70,71,88</sup> Studies reported barriers/facilitators within various general categories, including: environment-level, person-level, provider-level, healthcare system, accessibility of healthcare facilities, and accessible communication. Specific reported barriers are presented in Table 7, including: inaccessible communication method;<sup>70,71,88</sup> inaccessible facility;<sup>70,71,88</sup> lack of insurance;<sup>70,71</sup> and transportation issues.<sup>70,71</sup> Specific reported facilitators are also presented in Table 7, including: care continuity;<sup>70</sup> reliable transportation;<sup>70</sup> supportive family/caregivers;<sup>70</sup> and provider's understanding of a person's disability.<sup>70</sup>

**Table 7. Breast cancer screening – sensory disability: barriers and facilitators**

Screening Category	Barriers	Facilitators
<b>Environment-level</b>	<ul style="list-style-type: none"> <li>• Lacking support/advocacy</li> <li>• Transportation issue</li> </ul>	<ul style="list-style-type: none"> <li>• Reliable transportation</li> <li>• Supportive family/caregiver</li> </ul>
<b>Person-level</b>	<ul style="list-style-type: none"> <li>• Believing screening is not necessary</li> <li>• Difficulty with booking and attending appointments</li> <li>• Distrust of the healthcare system</li> <li>• Feeling vulnerable</li> <li>• Pain or discomfort of screening</li> <li>• Worry about family history of breast cancer</li> <li>• Lacking health education</li> </ul>	<ul style="list-style-type: none"> <li>• NA</li> </ul>
<b>Provider-level</b>	<ul style="list-style-type: none"> <li>• Negative attitude</li> <li>• No explanation before screening procedure</li> </ul>	<ul style="list-style-type: none"> <li>• Explanation provided before screening procedure</li> <li>• Good rapport with PwD</li> <li>• Understanding barriers</li> </ul>
<b>Healthcare system</b>	<ul style="list-style-type: none"> <li>• Lacking insurance</li> <li>• No reminder to receive screening</li> </ul>	<ul style="list-style-type: none"> <li>• Care continuity</li> </ul>
<b>Accessibility of facilities</b>	<ul style="list-style-type: none"> <li>• Inaccessible equipment</li> <li>• Inaccessible facility</li> </ul>	<ul style="list-style-type: none"> <li>• NA</li> </ul>
<b>Accessible communication</b>	<ul style="list-style-type: none"> <li>• Inaccessible communication method</li> </ul>	<ul style="list-style-type: none"> <li>• NA</li> </ul>

Abbreviations: NA = not applicable; PwD = people with a disability/person with a disability

### 3.2.2.2.4 Serious Mental Illness

We identified six studies that reported on barriers and/or facilitators to the receipt of breast cancer screening for people with serious mental illness (e.g., schizophrenia, bipolar disorder, major depressive disorder).<sup>61,62,70,72,81,82</sup> Studies reported barriers/facilitators within various general categories, including: environment-level, person-level, provider-level, healthcare system, accessibility of healthcare facilities, and policy-level. Specific reported barriers are presented in Table 8, including: patients believing screening is not necessary;<sup>61,70,81,82</sup> difficulty booking and attending appointment;<sup>61,70,82</sup> patient's fear and/or embarrassment;<sup>61,70,82</sup> provider lacking knowledge about providing care for people with disabilities;<sup>61,72</sup> people with disabilities lacking support/advocacy;<sup>61,70,72</sup> short appointment time;<sup>61,72,82</sup> and transportation issues.<sup>61,70,82</sup> Specific reported facilitators are also presented in Table 8, including: provider committed to health promotion;<sup>61,81,82</sup> and provider's understanding the barriers that people with disabilities face.<sup>61,70,72,81</sup>



### 3.2. Results, Key Question 1. Primary barriers and facilitators to the receipt of clinical preventive services

**Table 8. Breast cancer screening – serious mental illness disability: barriers and facilitators**

Screening Category	Barriers	Facilitators
<b>Environment-level</b>	<ul style="list-style-type: none"> <li>• Lacking support/advocacy</li> <li>• Transportation issue</li> </ul>	<ul style="list-style-type: none"> <li>• Reliable transportation</li> <li>• Supportive family/caregiver</li> </ul>
<b>Person-level</b>	<ul style="list-style-type: none"> <li>• Believing in faith as protection</li> <li>• Skeptical or believing that screening not necessary</li> <li>• Difficulty with booking and attending appointments</li> <li>• Distrust of the healthcare system</li> <li>• Fear and/or embarrassment</li> <li>• Feeling vulnerable</li> <li>• Lack of motivation</li> <li>• Lacking health education</li> <li>• Not understanding screening</li> <li>• Pain or discomfort with screening</li> <li>• Treatment fatigue from disability/comorbidities</li> <li>• Worry about family history of breast cancer</li> </ul>	<ul style="list-style-type: none"> <li>• Believing in faith as protection</li> <li>• Health conscious, patient</li> </ul>
<b>Provider-level</b>	<ul style="list-style-type: none"> <li>• Busyness with PwD's disability/comorbidities</li> <li>• Difficulty communication with PwD</li> <li>• Lack of knowledge about PwD</li> <li>• Lack of provider recommendation</li> <li>• Lack of rapport with provider</li> <li>• Negative attitude</li> <li>• No explanation before screening procedure</li> <li>• Not listening to/overlooking PwD</li> </ul>	<ul style="list-style-type: none"> <li>• Commitment to health promotion</li> <li>• Explanation provided before service</li> <li>• Good rapport with provider</li> <li>• Listening to PwD</li> <li>• Understanding barriers</li> </ul>
<b>Healthcare system</b>	<ul style="list-style-type: none"> <li>• Lack of communication about disability</li> <li>• Lack of female provider</li> <li>• Lacking insurance</li> <li>• Long wait time for appointments</li> <li>• No reminder to receive screening</li> <li>• Overwhelming number of reminders</li> <li>• Time constraint, provider</li> </ul>	<ul style="list-style-type: none"> <li>• Care continuity</li> <li>• Care coordination</li> <li>• Faster results</li> <li>• Reminder to receive screening</li> </ul>
<b>Accessibility of facilities</b>	<ul style="list-style-type: none"> <li>• Aggravating sensory environment</li> <li>• Inaccessible facility</li> <li>• Inaccessible mammography equipment</li> </ul>	<ul style="list-style-type: none"> <li>• Accessible facility</li> <li>• Familiar location</li> </ul>
<b>Policy-level</b>	<ul style="list-style-type: none"> <li>• Insurance not adhering to guidance</li> </ul>	<ul style="list-style-type: none"> <li>• NA</li> </ul>

Abbreviations: NA = not applicable; PwD = people with a disability/person with a disability

#### 3.2.2.2.5 Multiple Co-Occurring Disabilities

We identified two studies that reported on barriers and/or facilitators to the receipt of breast cancer screening for people with multiple co-occurring types of disability (e.g., physical and cognitive).<sup>66,75</sup> Studies reported barriers/facilitators at the provider level, the level of the healthcare system, and related to the accessibility of healthcare facilities. Specific reported barriers are presented in Table 9, including: inaccessible mammography machine,<sup>75</sup> and insufficient sedation.<sup>75</sup> Specific reported facilitators are also presented in Table 9, including: accessible changing area and equipment,<sup>66</sup> and an explanation of the procedure provided before the preventive service.<sup>66</sup>

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**Table 9. Breast cancer screening – multiple co-occurring disabilities: barriers and facilitators**

Screening Category	Barriers	Facilitators
Provider-level	<ul style="list-style-type: none"> <li>No explanation provided before service</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>
Healthcare system	<ul style="list-style-type: none"> <li>Lack of sedation during the procedure</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>
Accessibility of facilities	<ul style="list-style-type: none"> <li>Inaccessible mammography equipment</li> </ul>	<ul style="list-style-type: none"> <li>Accessible facility</li> </ul>

Abbreviations: NA = not applicable

#### 3.2.2.3 Cervical Cancer Screening

We identified 19 studies that reported on barriers and/or facilitators to the receipt of cervical cancer screening for people with disabilities.<sup>54-57,60-62,64,74,80,82,83,85,90-95</sup> Studies included people with physical disabilities (n=8), cognitive/intellectual/developmental disabilities (n=7), sensory disabilities (n=1), and serious mental illness (n=3), but no studies of people with multiple co-occurring disabilities. Studies reported barriers/facilitators within various general categories, including: environment-level, person-level, provider-level, healthcare system, accessibility of healthcare facilities, accessible communication, and policy-level (Tables 10 and 11, below). Studies used surveys (n=5) or a variety of qualitative methods, such as interviews or focus groups (n=14), to elicit information about barriers and/or facilitators from people with disabilities (n=14), caregivers (n=4), clinicians (n=7), or others (community leaders, n=1); five studies included two or more categories of participant. The general quality of studies was rated as good (n=15), fair (n=3), and poor (n=1), with common limitations including lack of an adequate response rate and missing data for survey designs, and unclear data collection methods for addressing the research question for qualitative designs. Specific barriers and facilitators are reported for each general type of disability in the following sections (3.2.2.3.1 – 3.2.2.3.4).

**Table 10. Summary of barriers for cervical cancer screening**

Category	Physical	Cognitive/Intellectual/Developmental	Sensory	Serious Mental Illness	Multiple Disabilities
Environment-level	✓	✓	--	✓	--
Person-level	✓	✓	--	✓	--
Provider-level	✓	✓	✓	✓	--
Healthcare system	--	✓	✓	✓	--
Accessibility of healthcare facilities	✓	✓	--	--	--
Accessible communication	--	✓	--	--	--
Policy-level	--	✓	--	--	--

✓ = denotes one or more studies in this category

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**Table 11. Summary of facilitators for cervical cancer screening**

Category	Physical	Cognitive/Intellectual/Developmental	Sensory	Serious Mental Illness	Multiple Disabilities
Environment-level	--	✓	--	--	--
Person-level	--	✓	--	✓	--
Provider-level	✓	✓	--	✓	--
Healthcare system	✓	✓	--	✓	--
Accessibility of healthcare facilities	✓	--	--	✓	--
Accessible communication	--	--	--	--	--
Policy-level	--	✓	--	--	--

✓ = denotes one or more studies in this category

#### 3.2.2.3.1 Physical Disability

We identified eight studies that reported on barriers and/or facilitators to the receipt of cervical cancer screening for people with physical disabilities.<sup>56,57,60,64,74,80,83,93</sup> Studies reported barriers/facilitators within various general categories, including: environment-level, person-level, provider-level, healthcare system, and accessibility of healthcare facilities. Specific reported barriers are presented in Table 12, including: inaccessible facility;<sup>57,60,83</sup> inaccessible equipment;<sup>57,74</sup> transportation issues;<sup>57,80</sup> patient’s fear and/or embarrassment;<sup>57,83</sup> and patients not understanding the screening process.<sup>57</sup> Specific reported facilitators are also presented in Table 12, including: accessible equipment;<sup>56,93</sup> longer appointments;<sup>93</sup> and providers having education and/or knowledge about patients with disabilities.<sup>57</sup>

**Table 12. Cervical cancer screening – physical disability: barriers and facilitators**

Screening Category	Barriers	Facilitators
Environment-level	<ul style="list-style-type: none"> <li>• Transportation issue</li> </ul>	<ul style="list-style-type: none"> <li>• NA</li> </ul>
Person-level	<ul style="list-style-type: none"> <li>• Fear and/or embarrassment</li> <li>• Feeling dependent on others</li> <li>• Not understanding screening process</li> <li>• Pain or discomfort with screening</li> <li>• Time constraints</li> </ul>	<ul style="list-style-type: none"> <li>• NA</li> </ul>
Provider-level	<ul style="list-style-type: none"> <li>• Lack of provider recommendation</li> <li>• Lack of rapport with provider</li> <li>• Negative attitude toward patient/ableism</li> <li>• Not listening to person with disabilities</li> <li>• Relying on provider to perform or order screening</li> </ul>	<ul style="list-style-type: none"> <li>• Assistance with dressing</li> <li>• Education and/or knowledge about PwD</li> <li>• Listening to PwD</li> <li>• Mobility assistance</li> </ul>
Healthcare system	<ul style="list-style-type: none"> <li>• NA</li> </ul>	<ul style="list-style-type: none"> <li>• Longer appointments</li> </ul>
Accessibility of facilities	<ul style="list-style-type: none"> <li>• Inaccessible equipment</li> <li>• Inaccessible facility</li> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• Accessible equipment</li> </ul>

Abbreviations: NA = not applicable; PwD = people with disabilities/person with a disability

#### 3.2.2.3.2 Cognitive/Intellectual/Developmental Disability

We identified seven studies that reported on barriers and/or facilitators to the receipt of cervical cancer screening for people with cognitive, intellectual, or developmental

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disabilities.<sup>54,55,85,91,92,94,95</sup> Studies reported barriers/facilitators within various general categories, including: environment-level, person-level, provider-level, healthcare system, accessibility of healthcare facilities, accessible communication, and policy-level. Specific reported barriers are presented in Table 13, including: provider misconceptions about patient’s sexual activity and need for screening;<sup>54,55,85,91,92</sup> patient’s fear and/or embarrassment;<sup>55,85,91,95</sup> patient lacking insurance;<sup>54,85</sup> literacy issues;<sup>94,95</sup> provider time constraints;<sup>92,95</sup> patient distrusting the healthcare system<sup>54</sup> or not understanding the screening process;<sup>54,95</sup> patient’s pain or discomfort with screening;<sup>55,95</sup> and clinician not providing an explanation before the screening procedure.<sup>55,91</sup> Specific reported facilitators are also presented in Table 13, including: clinician providing an explanation before the screening procedure;<sup>85,94,95</sup> patient having good rapport with provider;<sup>91,95</sup> supportive family or caregiver;<sup>54,91</sup> a female provider;<sup>55,91</sup> and the provider listening to the person with a disability.<sup>55,95</sup>

**Table 13. Cervical cancer screening – cognitive/intellectual/developmental disability: barriers and facilitators**

Screening Category	Barriers	Facilitators
<b>Environment-level</b>	<ul style="list-style-type: none"> <li>History of sexual assault</li> <li>Transportation issue</li> </ul>	<ul style="list-style-type: none"> <li>Chaperone</li> <li>Supportive family/caregiver</li> </ul>
<b>Person-level</b>	<ul style="list-style-type: none"> <li>Distrust of the healthcare system</li> <li>Fear and/or embarrassment</li> <li>Inability to give informed consent</li> <li>Lacking health education</li> <li>Not understanding screening process</li> <li>Pain or discomfort with screening</li> </ul>	<ul style="list-style-type: none"> <li>Family history</li> <li>Learning cancer symptoms</li> </ul>
<b>Provider-level</b>	<ul style="list-style-type: none"> <li>Ableism</li> <li>Believing screening not necessary or feasible for PwD</li> <li>Difficulty communicating with person with IDD</li> <li>Lack of knowledge about PwD</li> <li>Misconceptions about sexual activity and need for screening</li> <li>No explanation before screening procedure</li> <li>Not providing basic info to PwD</li> <li>Provider being unprepared</li> </ul>	<ul style="list-style-type: none"> <li>Adjusting procedures</li> <li>Encouraging patient control of screening process</li> <li>Explanation provided before screening procedure</li> <li>Good rapport with provider</li> <li>Knowledge of individual patient and preferences</li> <li>Listening to PwD</li> <li>Provider using accessible communication</li> <li>Providing basic info to PwD</li> </ul>
<b>Healthcare system</b>	<ul style="list-style-type: none"> <li>Lack of care coordination</li> <li>Lacking insurance</li> <li>Time constraints, provider</li> </ul>	<ul style="list-style-type: none"> <li>Female provider</li> <li>Specialist referral</li> </ul>
<b>Accessibility of facilities</b>	<ul style="list-style-type: none"> <li>Inaccessible facility</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>
<b>Accessible communication</b>	<ul style="list-style-type: none"> <li>Lacking internet access</li> <li>Literacy issues</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>
<b>Policy-level</b>	<ul style="list-style-type: none"> <li>Caregiver lacking decision-making authority</li> </ul>	<ul style="list-style-type: none"> <li>Guidance documents</li> </ul>

Abbreviations: IDD = intellectual/developmental disability; NA = not applicable; PwD = people with disabilities/person with a disability

#### 3.2.2.3.3 Sensory Disability

We identified one study that reported on barriers to the receipt of cervical cancer screening for people with sensory disabilities (visual impairment),<sup>90</sup> and no study of D/deaf people. The study reported barriers within two general categories, provider-level and healthcare system.

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Specific reported barriers were: not providing an explanation before the screening procedure; and not sending a reminder to receive screening (Table 14).

**Table 14. Cervical cancer screening – sensory disability: barriers and facilitators**

Screening Category	Barriers	Facilitators
Provider-level	<ul style="list-style-type: none"> <li>No explanation provided before service</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>
Healthcare system	<ul style="list-style-type: none"> <li>No reminder to receive screening</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>

Abbreviations: NA = not applicable

#### 3.2.2.3.4 Serious Mental Illness

We identified three studies that reported on barriers and/or facilitators to the receipt of cervical cancer screening for people with serious mental illness (e.g., schizophrenia, bipolar disorder, major depressive disorder).<sup>61,62,82</sup> Studies reported barriers/facilitators within various general categories, including: environment-level, person-level, provider-level, healthcare system, and accessibility of healthcare facilities. Specific reported barriers are presented in Table 15, including: patient’s fear and/or embarrassment;<sup>61,82</sup> transportation issues;<sup>61,82</sup> lack of care coordination;<sup>61,82</sup> provider time constraints;<sup>61,82</sup> the person with disability not booking and attending appointments,<sup>61,82</sup> or lacking motivation to receive screening;<sup>61,82</sup> and lack of provider recommendation for screening.<sup>62</sup> Most reported facilitators were provider-related, including the person with a disability having good rapport with the provider.<sup>61,82</sup> (Table 15).

**Table 15. Cervical cancer screening – serious mental illness: barriers and facilitators**

Screening Category	Barriers	Facilitators
Environment-level	<ul style="list-style-type: none"> <li>Environment aggravates symptoms</li> <li>Transportation issue</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>
Person-level	<ul style="list-style-type: none"> <li>Difficulty booking and attending appointments</li> <li>Fear and/or embarrassment</li> <li>Lack of motivation</li> <li>Not understanding screening process</li> <li>Pain or discomfort with screening</li> <li>Psychiatric symptoms</li> </ul>	<ul style="list-style-type: none"> <li>Health consciousness</li> </ul>
Provider-level	<ul style="list-style-type: none"> <li>Lack of knowledge about PwD</li> <li>Lack of rapport with provider</li> <li>Lack of provider recommendation</li> <li>Priority on acute needs</li> </ul>	<ul style="list-style-type: none"> <li>Commitment to health promotion</li> <li>Education and/or knowledge about PwD</li> <li>Good rapport with provider</li> <li>Provider using accessible communication</li> <li>Understanding barriers</li> </ul>
Healthcare system	<ul style="list-style-type: none"> <li>Lack of care coordination</li> <li>Lack of resources</li> <li>Time constraints, provider</li> <li>Wait time for appointments</li> </ul>	<ul style="list-style-type: none"> <li>Care coordination</li> <li>Reminder to receive screening</li> </ul>
Accessibility of facilities	<ul style="list-style-type: none"> <li>NA</li> </ul>	<ul style="list-style-type: none"> <li>Familiar location</li> </ul>

Abbreviations: NA = not applicable; PwD = people with disabilities/person with a disability

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### 3.2.2.4 Colorectal Cancer Screening

We identified six studies that reported on barriers and/or facilitators to the receipt of colorectal cancer screening for people with disabilities.<sup>60-62,64,80,96</sup> Studies included people with physical disabilities (n=4) and serious mental illness (n=2). No studies reported on people with cognitive/intellectual/developmental disabilities, sensory disabilities, or multiple co-occurring disabilities. Studies reported barriers/facilitators within various general categories, including: environment-level, person-level, provider-level, healthcare system, and accessibility of healthcare facilities (Tables 16 and 17, below). Studies used surveys (n=3) or a variety of qualitative methods, such as interviews or focus groups (n=3), to elicit information about barriers and/or facilitators from people with disabilities (n=6) and/or clinicians (n=1); one study included both patients and providers. The general quality of the studies was assessed to be good (n=4) to fair (n=2), with common limitations including missing survey data and uncertainty regarding the coherence of data sources, data collection, and analysis/interpretation for a qualitative study. Specific barriers and facilitators are reported for each general type of disability in the following sections (3.2.2.4.1 – 3.2.2.4.2).

**Table 16. Summary of barriers for colorectal cancer screening**

Category	Physical	Cognitive/Intellectual/Developmental	Sensory	Serious Mental Illness	Multiple Disabilities
Environment-level	✓	--	--	✓	--
Person-level	✓	--	--	✓	--
Provider-level	✓	--	--	✓	--
Healthcare system	✓	--	--	✓	--
Accessibility of healthcare facilities	✓	--	--	--	--
Accessible communication	--	--	--	--	--
Policy-level	--	--	--	--	--

✓ = denotes one or more studies in this category

**Table 17. Summary of facilitators for colorectal cancer screening**

Category	Physical	Cognitive/Intellectual/Developmental	Sensory	Serious Mental Illness	Multiple Disabilities
Environment-level	--	--	--	--	--
Person-level	--	--	--	✓	--
Provider-level	--	--	--	✓	--
Healthcare system	--	--	--	✓	--
Accessibility of healthcare facilities	--	--	--	✓	--
Accessible communication	--	--	--	--	--
Policy-level	--	--	--	--	--

✓ = denotes 1 or more studies in this category

### 3.2. Results, Key Question 1. Primary barriers and facilitators to the receipt of clinical preventive services

#### 3.2.2.4.1 Physical Disability

We identified four studies that reported on barriers to the receipt of colorectal cancer screening for people with physical disabilities.<sup>60,64,80,96</sup> No study reported facilitators for colorectal cancer screening for people with physical disabilities. Studies reported barriers within various general categories, including: environment-level, person-level, provider-level, healthcare system, and accessibility of healthcare facilities. Specific reported barriers are presented in Table 18, including: inaccessible test preparation process;<sup>60,64</sup> transportation issue;<sup>80,96</sup> and lack of provider recommendation.<sup>60,64</sup>

**Table 18. Colorectal cancer screening – physical disability: barriers and facilitators**

Screening Category	Barriers	Facilitators
Environment-level	<ul style="list-style-type: none"> <li>Lacking support/advocacy</li> <li>Transportation issue</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>
Person-level	<ul style="list-style-type: none"> <li>Fear and/or embarrassment</li> <li>Feeling dependent on others</li> <li>Not understanding screening process</li> <li>Socioeconomic barriers (e.g. fixed income, inadequate insurance)</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>
Provider-level	<ul style="list-style-type: none"> <li>Lack of provider recommendation</li> <li>Not listening to PwD</li> <li>Relying on provider to perform or order screening</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>
Healthcare system	<ul style="list-style-type: none"> <li>Wait time for appointments</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>
Accessibility of facilities	<ul style="list-style-type: none"> <li>Inaccessible equipment</li> <li>Inaccessible facility</li> <li>Inaccessible test preparation process</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>

Abbreviations: NA = not applicable; PwD = people with disabilities/person with a disability

#### 3.2.2.4.2 Serious Mental Illness

We identified two studies that reported on barriers and/or facilitators to the receipt of colorectal cancer screening for people with serious mental illness (e.g., schizophrenia, bipolar disorder, major depressive disorder).<sup>61,62</sup> Studies reported barriers/facilitators within various general categories, including: environment-level, person-level, provider-level, healthcare system, and accessibility of healthcare facilities. Specific reported barriers are presented in Table 19, including: patient’s fear and/or embarrassment;<sup>61</sup> lack of provider recommendation to receive screening;<sup>62</sup> and provider time constraints.<sup>61</sup> Specific reported facilitators are also presented in Table 19 and were most often provider-level, including: provider’s education and/or knowledge about people with disabilities,<sup>61</sup> and using accessible communication.<sup>61</sup>

**Table 19. Colorectal cancer screening – serious mental illness: barriers and facilitators**

Screening Category	Barriers	Facilitators
Environment-level	<ul style="list-style-type: none"> <li>Environment aggravates mental health symptoms</li> <li>Transportation issues</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>
Person-level	<ul style="list-style-type: none"> <li>Difficulty booking and attending appointments</li> <li>Fear and/or embarrassment</li> <li>Lack of motivation</li> <li>Not understanding screening process</li> </ul>	<ul style="list-style-type: none"> <li>Health consciousness</li> </ul>
Provider-level	<ul style="list-style-type: none"> <li>Lack of knowledge about PwD</li> </ul>	<ul style="list-style-type: none"> <li>Commitment to health promotion</li> </ul>

### 3.2. Results, Key Question 1. Primary barriers and facilitators to the receipt of clinical preventive services

Screening Category	Barriers	Facilitators
	<ul style="list-style-type: none"> <li>Lack of provider recommendation</li> <li>Lack of rapport with provider</li> </ul>	<ul style="list-style-type: none"> <li>Education and/or knowledge about PwD</li> <li>Good rapport with provider</li> <li>Provider using accessible communication</li> <li>Understanding barriers</li> </ul>
<b>Healthcare system</b>	<ul style="list-style-type: none"> <li>Lack of care coordination</li> <li>Lack of resources for health service delivery (not further defined)</li> <li>Time constraints, provider</li> </ul>	<ul style="list-style-type: none"> <li>Care coordination</li> <li>Reminder to receive screening</li> </ul>
<b>Accessibility of facilities</b>	<ul style="list-style-type: none"> <li>NA</li> </ul>	<ul style="list-style-type: none"> <li>Familiar location</li> </ul>

Abbreviations: NA = not applicable; PwD = people with disabilities/person with a disability

#### 3.2.2.5 Depression Risk Screening in Adults

We identified three studies that reported on barriers and/or facilitators to the receipt of screening for depression for adults with disabilities.<sup>53,97,98</sup> Studies included people with cognitive/intellectual/developmental disabilities (n=1), and sensory disabilities (n=2). No studies reported on people with physical disabilities, serious mental illness, or multiple co-occurring disabilities. Studies reported barriers/facilitators at the person-level, provider-level, healthcare system, and policy-level (Tables 20 and 21, below). Studies used qualitative (n=1) and mixed-methods (n=2) approaches, to elicit information about barriers or facilitators from people with disabilities or caregivers (n=1) and/or clinicians (n=3). The general quality of each study was assessed as good. Specific barriers and facilitators are reported for each general type of disability in the following sections (3.2.2.5.1 – 3.2.2.5.2).

**Table 20. Summary of reported categories of barriers for screening for depression risk on adults**

Category	Physical	Cognitive/Intellectual/Developmental	Sensory	Serious Mental Illness	Multiple Disabilities
<b>Environment-level</b>	--	--	--	--	--
<b>Person-level</b>	--	--	✓	--	--
<b>Provider-level</b>	--	✓	✓	--	--
<b>Healthcare system</b>	--	--	✓	--	--
<b>Accessibility of healthcare facilities</b>	--	--	--	--	--
<b>Accessible communication</b>	--	--	--	--	--
<b>Policy-level</b>	--	--	--	--	--

✓ = denotes one or more studies in this category



### 3.2. Results, Key Question 1. Primary barriers and facilitators to the receipt of clinical preventive services

**Table 21. Summary of reported categories of facilitators for screening for depression risk on adults**

Category	Physical	Cognitive/Intellectual/Developmental	Sensory	Serious Mental Illness	Multiple Disabilities
Environment-level	--	--	--	--	--
Person-level	--	--	--	--	--
Provider-level	--	✓		--	--
Healthcare system	--	--	--	--	--
Accessibility of healthcare facilities	--	--	--	--	--
Accessible communication	--	--	--	--	--
Policy-level	--	--	✓	--	--

✓ = denotes one or more studies in this category

#### 3.2.2.5.1 Cognitive/Intellectual/Developmental Disability

We identified one study that reported on barriers and/or facilitators to the receipt of screening for depression for adults with cognitive, intellectual, or developmental disabilities.<sup>53</sup> The study – which was also included for anxiety disorder screening and described in that section, above – used focus groups and interviews to understand barriers and facilitators to the implementation of clinical practice guidelines for depression and anxiety in patients with dementia or Parkinson’s disease. Although most of the reported barriers/facilitators related to treatment/management or to other aspects of diagnosis, some barriers and facilitators related directly or indirectly to screening itself. All of the barriers and facilitators related to screening were in the provider-level category and appeared to be reported by physicians. The reported barriers included: providers being unprepared, misconceptions about scope of practice, lack of knowledge about people with disabilities, and providers’ belief that screening tools have limitations. The reported facilitators included: use of screening tools, physician awareness of scope of practice, and comprehensive knowledge of the procedure (Table 22).

**Table 22. Screening for depression risk in adults – cognitive/intellectual/developmental disability: barriers and facilitators**

Screening Category	Barriers	Facilitators
Provider-level	<ul style="list-style-type: none"> <li>• Provider being unprepared</li> <li>• Misconceptions about scope of practice</li> <li>• Lack of knowledge about PwD</li> <li>• Belief that screening tools have limitations</li> </ul>	<ul style="list-style-type: none"> <li>• Use of screening tools</li> <li>• Awareness of scope of practice</li> <li>• Comprehensive knowledge of procedure, from screening to diagnosis</li> </ul>

Abbreviations: PwD = people with disabilities/person with a disability

#### 3.2.2.5.2 Sensory Disability

We identified two studies that reported on barriers and/or facilitators to the receipt of screening for depression for adults with low vision.<sup>97,98</sup> Each study reported on a separate phase of a single project conducted within a national low-vision care service in Wales, UK, including an intervention that is described in the Results for Key Question 2.<sup>97</sup> Studies used a mix of interviews and surveys with optometrists, dispensing opticians, and an ophthalmic practitioner. Studies reported barriers at the person-level, provider-level, and healthcare system, and a facilitator at the policy-level. Specific reported barriers included: patients feeling fear and/or

### 3.2. Results, Key Question 1. Primary barriers and facilitators to the receipt of clinical preventive services

embarrassment;<sup>97,98</sup> patients having distrust of the healthcare system;<sup>97</sup> providers being unprepared;<sup>97,98</sup> and long wait times for appointments.<sup>97</sup> The only reported facilitator was the availability and/or use of guidance documents.<sup>98</sup> (Table 23).

**Table 23. Screening for depression risk in adults – sensory disability: barriers and facilitators**

Screening Category	Barriers	Facilitators
Person-level	<ul style="list-style-type: none"> <li>• Fear and/or embarrassment</li> <li>• Distrust of the healthcare system</li> </ul>	<ul style="list-style-type: none"> <li>• NA</li> </ul>
Provider-level	<ul style="list-style-type: none"> <li>• Provider being unprepared</li> </ul>	<ul style="list-style-type: none"> <li>• NA</li> </ul>
Healthcare system	<ul style="list-style-type: none"> <li>• Wait time for appointments</li> </ul>	<ul style="list-style-type: none"> <li>• NA</li> </ul>
Policy-level	<ul style="list-style-type: none"> <li>• NA</li> </ul>	<ul style="list-style-type: none"> <li>• Guidance documents</li> </ul>

Abbreviations: NA = not applicable

#### 3.2.2.6 Screening for HIV Infection

We identified one study that reported on barriers and/or facilitators to the receipt of HIV screening for people with sensory disabilities.<sup>99</sup> No studies reported on people with physical disabilities, cognitive/intellectual/developmental disabilities, serious mental illness, or multiple co-occurring disabilities. The study used focus groups (21 focus groups with a total of 134 participants) and individual interviews (n=7) among D/deaf people in the state of New York, USA, to assess general knowledge about HIV/AIDS and barriers to HIV/AIDS education and prevention, including HIV testing. The general quality of the study was rated as good. The study reported barriers at the person-level and at the level of inaccessible communication. Specific reported barriers included: inaccessible communication methods related to a lack of available interpreters and breaches of confidentiality that come with the use of interpreters, specifically the presence of guardians in appointments for adolescents (Table 24).

**Table 24. Screening for HIV infection – sensory disability: barriers and facilitators**

Screening Category	Barriers	Facilitators
Person-level	<ul style="list-style-type: none"> <li>• Breach of confidentiality when using interpreters, adults and adolescents</li> </ul>	<ul style="list-style-type: none"> <li>• NA</li> </ul>
Accessible communication	<ul style="list-style-type: none"> <li>• Inaccessible communication due to lack of interpreter</li> </ul>	<ul style="list-style-type: none"> <li>• NA</li> </ul>

Abbreviations: NA = not applicable

#### 3.2.2.7 Unhealthy Alcohol Use Screening

We identified two studies that reported on barriers and/or facilitators to the receipt of unhealthy alcohol use screening for people with cognitive, intellectual, or developmental disabilities.<sup>100,101</sup> No studies reported on people with physical disabilities, sensory disabilities, serious mental illness, or multiple co-occurring disabilities. Both studies were conducted by the same group of investigators in the UK. One study used surveys sent to managers of memory clinics (n=35) and focus groups of healthcare workers at memory clinics, including dementia nurse specialists, social workers, psychologists, and occupational therapists (2 focus groups with a total of 12 participants), to understand current practice, barriers, and facilitators to identifying and responding to alcohol problems among patients in memory clinics.<sup>101</sup> The other study used semi-structured interviews of people older than 65 years with cognitive impairment (n=10) receiving services in memory clinics, to understand the feasibility and acceptability of routine screening for alcohol misuse.<sup>100</sup> The general quality of both studies was rated as good.

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The studies reported barriers/facilitators within various general categories, including: environment-level, person-level, provider-level, healthcare system level, and the level of accessible communication. Specific reported barriers included: patients' lack of confidence in answering the screening questions;<sup>100</sup> patients' fear and/or embarrassment;<sup>100,101</sup> providers being unprepared;<sup>101</sup> provider's belief that screening for alcohol use is not within purview of a memory clinic;<sup>101</sup> time constraints for the provider;<sup>101</sup> and difficulty communicating with people with IDD.<sup>100,101</sup> Specific reported facilitators included: the use of a chaperone;<sup>100,101</sup> providers adjusting procedures to accommodate patient's disability;<sup>101</sup> and accessible communication methods.<sup>100</sup> (Table 25).

**Table 25. Unhealthy alcohol use screening – cognitive/intellectual/developmental disability: barriers and facilitators**

Screening Category	Barriers	Facilitators
<b>Environment-level</b>	<ul style="list-style-type: none"> <li>• NA</li> </ul>	<ul style="list-style-type: none"> <li>• Chaperone</li> </ul>
<b>Person-level</b>	<ul style="list-style-type: none"> <li>• Lack of confidence in answering screening questions</li> <li>• Fear and/or embarrassment</li> </ul>	<ul style="list-style-type: none"> <li>• NA</li> </ul>
<b>Provider-level</b>	<ul style="list-style-type: none"> <li>• Provider being unprepared</li> <li>• Belief that screening for alcohol use not within purview of memory clinic</li> <li>• Lack of experience</li> </ul>	<ul style="list-style-type: none"> <li>• Adjusting procedures to accommodate patient's disability</li> </ul>
<b>Healthcare system</b>	<ul style="list-style-type: none"> <li>• Time constraints, provider</li> </ul>	<ul style="list-style-type: none"> <li>• NA</li> </ul>
<b>Accessible communication</b>	<ul style="list-style-type: none"> <li>• Difficulty communicating with person with IDD</li> </ul>	<ul style="list-style-type: none"> <li>• Accessible communication methods</li> </ul>

Abbreviations: NA = not applicable; IDD = intellectual/developmental disability

#### 3.2.2.8 Interventions to Prevent Falls in Community-Dwelling Adults

We identified one study that reported on barriers and/or facilitators to the receipt of interventions to prevent falls for community-dwelling adults with cognitive, intellectual, or developmental disabilities.<sup>102</sup> No studies reported on people with physical disabilities, sensory disabilities, serious mental illness, or multiple co-occurring disabilities. The study was designed to provide information to guide the development of a falls prevention intervention for people with dementia. The study used semi-structured interviews (n=19) with nurses, physiotherapists, occupational therapists, and a psychiatrist in the UK, who work in memory assessment or falls prevention services for people with dementia. The general quality of the study was rated as good. The study reported barriers/facilitators within various general categories, including: person-level, provider-level, and healthcare system level. Specific reported barriers included: lack of healthcare system resources and lack of care coordination. Specific reported facilitators included: patients' feelings of support and motivation, providers' knowledge of individual patients and preferences, and healthcare systems that bring services to people with disabilities, produce faster results and care continuity (Table 26).

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**Table 26. Falls prevention in community-dwelling adults – cognitive/intellectual/developmental disability: barriers and facilitators**

Screening Category	Barriers	Facilitators
Person-level	<ul style="list-style-type: none"> <li>• NA</li> </ul>	<ul style="list-style-type: none"> <li>• Support and motivation</li> </ul>
Provider-level	<ul style="list-style-type: none"> <li>• NA</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge of individual patient and preferences</li> </ul>
Healthcare system	<ul style="list-style-type: none"> <li>• Lack of resources</li> <li>• Lack of care coordination</li> </ul>	<ul style="list-style-type: none"> <li>• Bringing service to PwD</li> <li>• Faster results</li> <li>• Care continuity</li> </ul>

Abbreviations: NA = not applicable; PwD = people with disabilities/person with a disability

#### 3.2.2.9 Behavioral Counseling to Promote Healthy Diet and Physical Activity to Prevent Cardiovascular Disease

We identified one study that reported on barriers and/or facilitators to the receipt of counseling to promote healthy diet and physical activity to prevent CVD, including advice on healthy diet and physical activity, for people with disabilities.<sup>103</sup> The study included people with serious mental illness (schizophrenia and bipolar disorder). No studies reported on people with physical disabilities, cognitive/intellectual/developmental disabilities, sensory disabilities, or multiple co-occurring disabilities. The study reported barriers/facilitators within two general categories: person-level and healthcare system level. It used a qualitative survey to elicit information about barriers and/or facilitators from people with disabilities and clinicians. The general quality of the study was rated as fair, with a limitation of missing data and uncertainty if measures were validated on the population. Specific reported barriers included patient’s lack of motivation and provider time constraints; the only reported facilitator was screening conducted in the primary care setting (Table 27).

**Table 27. Cardiovascular screening, diet, and exercise – serious mental illness: barriers and facilitators**

Screening Category	Barriers	Facilitators
Person-level	<ul style="list-style-type: none"> <li>• Lack of motivation</li> <li>• Booking and attending appointments</li> </ul>	<ul style="list-style-type: none"> <li>• NA</li> </ul>
Healthcare system	<ul style="list-style-type: none"> <li>• Time constraints, provider</li> </ul>	<ul style="list-style-type: none"> <li>• Screening in a primary care setting</li> </ul>

Abbreviations: NA = not applicable

#### 3.2.2.10 Sexually Transmitted Infection Prevention

We identified three studies that reported on barriers and/or facilitators to the receipt of preventive services for sexually transmitted infections (STIs) for people with disabilities.<sup>104-106</sup> Studies included people with physical disabilities (n=1) and serious mental illness (n=2). No studies reported on people with cognitive/intellectual/developmental disabilities, sensory disabilities, or multiple co-occurring disabilities. Studies reported barriers/facilitators within various general categories, including: environment-level, person-level, provider-level, and healthcare system level. Studies used qualitative methods, including interviews (n=2) and focus groups (n=1), to elicit information about barriers and/or facilitators from people with disabilities (n=1), clinicians (n=1), or others (mental health case managers, n=1). The general quality of studies was assessed as good (n=2) or fair (n=1), with a limitation related to uncertainty about the adequacy of the approach and data collection methods. Specific barriers and facilitators are reported for each general type of disability in the following sections (3.2.2.10.1 – 3.2.2.10.2).

## 3.2. Results, Key Question 1. Primary barriers and facilitators to the receipt of clinical preventive services

### 3.2.2.10.1 Physical Disability

We identified one study that reported on barriers and/or facilitators to the receipt of preventive services for STIs for people with physical disabilities.<sup>106</sup> The study reported one person-level barrier: a disability that makes the preventive intervention more difficult to use (in this case, barrier contraception when the person with a disability lacked pelvic muscle tone). No facilitators were reported (Table 28).

**Table 28. Sexually transmitted infection prevention – physical disability: barriers and facilitators**

Screening Category	Barriers	Facilitators
Person-level	<ul style="list-style-type: none"> <li>Disability makes intervention more difficult to use</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>

Abbreviations: NA = not applicable

### 3.2.2.10.2 Serious Mental Illness

We identified two studies that reported on barriers and/or facilitators to the receipt of preventive services for STIs for people with serious mental illness (e.g., schizophrenia, bipolar disorder, major depressive disorder).<sup>104,105</sup> Studies reported barriers/facilitators within various general categories, including: environment-level, person-level, provider-level, and healthcare system. Specific reported barriers are presented in Table 29, including: provider’s discomfort discussing sexuality with people with disabilities<sup>104,105</sup> and liability associated with services provided (e.g. discussing use of clean needles with intravenous drug users).<sup>105</sup> Specific reported facilitators are also presented in Table 29, including: patients receiving education or information from peers<sup>105</sup> and providers’ education and/or knowledge about people with disabilities.<sup>104</sup>

**Table 29. Sexually transmitted infection prevention –serious mental illness: barriers and facilitators**

Screening Category	Barriers	Facilitators
Environment-level	<ul style="list-style-type: none"> <li>NA</li> </ul>	<ul style="list-style-type: none"> <li>Education in community groups</li> <li>Education/information from peers</li> <li>Providing support/advocacy</li> </ul>
Person-level	<ul style="list-style-type: none"> <li>Cultural or religious barriers to interventions</li> <li>Psychiatric symptoms</li> </ul>	<ul style="list-style-type: none"> <li>NA</li> </ul>
Provider-level	<ul style="list-style-type: none"> <li>Believing screening not necessary or feasible for PwD</li> <li>Discomfort discussing sexuality</li> <li>Focus on acute care</li> <li>Lack of knowledge about PwD</li> <li>Lack of rapport with provider</li> <li>Misconceptions about sexual activity and need for screening</li> </ul>	<ul style="list-style-type: none"> <li>Comprehensive knowledge of procedure</li> <li>Education and/or knowledge about PwD</li> <li>Providing basic info to PwD</li> </ul>
Healthcare system	<ul style="list-style-type: none"> <li>Lack of resources for health service delivery (not further defined)</li> <li>Liability associated with services provided</li> </ul>	<ul style="list-style-type: none"> <li>Care coordination</li> <li>Insurance coverage</li> <li>Support of system administrators</li> </ul>

Abbreviations: NA = not applicable; PwD = people with disabilities/person with a disability

### 3.2.3 Results, Key Question 1a. Barriers/facilitators according to preventive service

#### 3.2.3 Key Question 1a. How do these barriers/facilitators vary according to preventive service?

Table 30 shows the number of studies that reported barriers and/or facilitators – presented by category of barrier/facilitator (environment-level, person-level, provider-level, healthcare system-level, accessibility of healthcare facility, accessible communication), within each preventive service and according to disability type. The individual studies within each category of barrier/facilitator and disability type are listed in the table in Appendix G. As previously noted, the table shows that the largest number of studies pertained to breast cancer screening and/or cervical cancer screening, and addressed barriers/facilitators for people with cognitive/intellectual/ developmental disabilities or physical disabilities. The table also shows that the general categories of reported barriers/facilitators varied across the different preventive services – with barriers/facilitators at the person-level, provider-level, and healthcare system-level reported most commonly, and policy-level barriers/facilitators rarely reported.

**Environment-level** barriers/facilitators were reported for five preventive services (breast cancer screening; cervical cancer screening; colorectal cancer screening; screening for unhealthy alcohol use; and behavioral counselling to prevent sexually transmitted infections). For breast cancer screening, environment-level barriers and facilitators were reported for all types of disability. For cervical cancer screening, barriers were reported for physical disability, cognitive disability, and serious mental illness; with facilitators reported for cognitive disability. For colorectal cancer screening, barriers were reported only for physical disability and serious mental illness. For screening for unhealthy alcohol use, facilitators were reported only for people with cognitive disabilities. For counselling to prevent STIs, facilitators were reported for people with serious mental illness.

**Person-level** barriers/facilitators were reported for nine preventive services (breast cancer screening; cervical cancer screening; colorectal cancer screening; screening for depression risk in adults; screening for HIV infection; screening for unhealthy alcohol use; interventions for falls prevention in community-dwelling older adults; counselling for healthy diet and physical activity for CVD prevention; and behavioral counselling to prevent sexually transmitted infections). For breast cancer screening, person-level barriers and facilitators were reported for all types of disability, except facilitators for sensory disability. For cervical cancer screening, barriers were reported for physical disability, cognitive disability, and serious mental illness; with facilitators reported for cognitive disability and serious mental illness. For colorectal cancer screening, barriers were reported only for physical disability and serious mental illness, with facilitators reported for serious mental illness. For counselling to prevent STIs, barriers were reported for physical disability and people with serious mental illness. For other preventive services, barriers or facilitators were reported for only one type of disability: depression screening (barriers for sensory disability); HIV screening (barriers for sensory disability); counselling for CVD prevention (barriers for serious mental illness); screening for unhealthy alcohol use (barriers for cognitive disability); interventions for falls prevention (facilitators for cognitive disability).

**Provider-level** barriers/facilitators were reported for eight preventive services (screening for anxiety disorder in adults; breast cancer screening; cervical cancer screening; colorectal cancer screening; screening for depression risk in adults; screening for unhealthy alcohol use; interventions for falls prevention in community-dwelling older adults; and behavioral counselling to prevent sexually transmitted infections). For breast cancer screening, provider-level barriers and facilitators were reported for all types of disability. For cervical cancer

### 3.2.3 Results, Key Question 1a. Barriers/facilitators according to preventive service

screening, barriers and facilitators were reported for all types of disability, except facilitators for sensory disability. For colorectal cancer screening, barriers were reported only for physical disability and serious mental illness, with facilitators reported for serious mental illness. For depression screening, barriers and facilitators were reported for cognitive disability, and barriers only were reported for sensory disability. For other preventive services, barriers or facilitators were reported for only one type of disability: anxiety screening (barriers and facilitators for cognitive disability); screening for unhealthy alcohol use (barriers and facilitators for cognitive disability); interventions for falls prevention (facilitators for cognitive disability), and counselling to prevent STIs (barriers and facilitators for serious mental illness).

**Healthcare system-level** barriers/facilitators were reported for eight preventive services (breast cancer screening; cervical cancer screening; colorectal cancer screening; screening for depression risk in adults; screening for unhealthy alcohol use; interventions for falls prevention in community-dwelling older adults; counselling for healthy diet and physical activity for CVD prevention; and behavioral counselling to prevent sexually transmitted infections). For breast cancer screening, healthcare system-level barriers and facilitators were reported for all types of disability. For cervical cancer screening, barriers and facilitators were reported for all types of disability, except barriers for physical disability and facilitators for sensory disability. For colorectal cancer screening, barriers were reported only for physical disability and serious mental illness, with facilitators reported for serious mental illness. For other preventive services, barriers and/or facilitators were reported for only one type of disability: depression screening (barriers for sensory disability); screening for unhealthy alcohol use (barriers for cognitive disability); interventions for falls prevention (barriers and facilitators for cognitive disability), counselling for CVD prevention (barriers and facilitators for serious mental illness); and counselling to prevent STIs (barriers and facilitators for serious mental illness).

Barriers/facilitators related to the **accessibility of healthcare facilities** were reported for three preventive services (breast cancer screening; cervical cancer screening; colorectal cancer screening). For breast cancer screening, barriers and facilitators related to the accessibility of healthcare facilities were reported for all types of disability, except facilitators for sensory disability. For cervical cancer screening, barriers and facilitators were reported for physical disability, with barriers only reported for cognitive disability and facilitators only reported for serious mental illness. For colorectal cancer screening, barriers were reported only for physical disability and facilitators were reported for serious mental illness.

Barriers/facilitators related to **accessible communication** were reported for four preventive services (breast cancer screening; cervical cancer screening; screening for HIV infection; screening for unhealthy alcohol use). For breast cancer screening, barriers and facilitators related to accessible communication were reported for all types of disability, except serious mental illness and facilitators for sensory disability. For other preventive services, barriers and/or facilitators were reported for only one type of disability: cervical cancer screening (barriers for cognitive disability); HIV screening (barriers for sensory disability); and screening for unhealthy alcohol use (barriers and facilitators for cognitive disability).

**Policy-level** barriers/facilitators were reported for three preventive services (breast cancer screening; cervical cancer screening; screening for depression risk in adults). For breast cancer screening, policy-level barriers were reported only cognitive disability and serious mental illness. For cervical cancer screening, barriers and facilitators were reported only for cognitive disability. For depression screening, facilitators only were reported for sensory disability.

### 3.2.3 Results, Key Question 1a. Barriers/facilitators according to preventive service

**Table 30. Barriers and facilitators by preventive service and type of disability**

USPSTF Clinical Preventive Service	Barrier/ Facilitator Factor Level	Physical Disability	Physical Disability	Cognitive Disability	Cognitive Disability	Sensory Disability	Sensory Disability	SMI Disability	SMI Disability	Multiple Disabilities	Multiple Disabilities
		<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>
Anxiety disorder screening for adults (n=1)	Environment	--	--	--	--	--	--	--	--	--	--
	Person	--	--	--	--	--	--	--	--	--	--
	Provider	--	--	n=1	n=1--	--	--	--	--	--	--
	Healthcare system	--	--	--	--	--	--	--	--	--	--
	Accessibility- HCF	--	--	--	--	--	--	--	--	--	--
	Accessible communication	--	--	--	--	--	--	--	--	--	--
	Policy	--	--	--	--	--	--	--	--	--	--
Breast cancer screening (n=36)	Environment	n=7	n=2	n=11	n=9	n=2	n=1	n=4	n=3	--	--
	Person	n=11	n=2	n=14	n=6	n=2	--	n=4	n=2	--	--
	Provider	n=12	n=8	n=11	n=8	n=1	n=3	n=4	n=5	--	n=1
	Healthcare system	n=4	n=2	n=4	n=6	n=2	n=1	n=5	n=4	n=1	--
	Accessibility- HCF	n=13	n=8	n=7	n=1	n=3	--	n=2	n=2	n=1	n=1
	Accessible communication	n=1	n=1	n=3	n=7	n=3	--	--	--	--	--
	Policy	--	--	n=1	--	--	--	n=1	--	--	--
Cervical cancer screening (n=19)	Environment	n=2	--	n=1	n=3	--	--	n=2	--	--	--
	Person	n=4	--	n=5	n=2	--	--	n=2	n=1	--	--
	Provider	n=5	n=3	n=7	n=6	n=1	--	n=3	n=2	--	--
	Healthcare system	--	n=1	n=5	n=3	n=1	--	n=2	n=1	--	--
	Accessibility- HCF	n=5	n=2	n=1	--	--	--	--	n=1	--	--
	Accessible communication	--	--	n=3	--	--	--	--	--	--	--
	Policy	--	--	n=1	n=1	--	--	--	--	--	--



### 3.2.3 Results, Key Question 1a. Barriers/facilitators according to preventive service

USPSTF Clinical Preventive Service	Barrier/ Facilitator Factor Level	Physical Disability	Physical Disability	Cognitive Disability	Cognitive Disability	Sensory Disability	Sensory Disability	SMI Disability	SMI Disability	Multiple Disabilities	Multiple Disabilities
		<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>
Colorectal cancer screening (n=6)	Environment	n=2	--	--	--	--	--	n=1	--	--	--
	Person	n=1	--	--	--	--	--	n=1	n=1	--	--
	Provider	n=3	--	--	--	--	--	n=2	n=1	--	--
	Healthcare system	n=1	--	--	--	--	--	n=1	n=1	--	--
	Accessibility- HCF	n=3	--	--	--	--	--	--	n=1	--	--
	Accessible communication	--	--	--	--	--	--	--	--	--	--
	Policy	--	--	--	--	--	--	--	--	--	--
Depression screening for adults (n=3)	Environment	--	--	--	--	--	--	--	--	--	--
	Person	--	--	--	--	n=2	--	--	--	--	--
	Provider	--	--	n=1	n=1	n=2	--	--	--	--	--
	Healthcare system	--	--	--	--	n=1	--	--	--	--	--
	Accessibility- HCF	--	--	--	--	--	--	--	--	--	--
	Accessible communication	--	--	--	--	--	--	--	--	--	--
	Policy	--	--	--	--	--	n=1	--	--	--	--
HIV infection screening (n=1)	Environment	--	--	--	--	--	--	--	--	--	--
	Person	--	--	--	--	n=1	--	--	--	--	--
	Provider	--	--	--	--	--	--	--	--	--	--
	Healthcare system	--	--	--	--	--	--	--	--	--	--
	Accessibility- HCF	--	--	--	--	--	--	--	--	--	--
	Accessible communication	--	--	--	--	n=1	--	--	--	--	--
	Policy	--	--	--	--	--	--	--	--	--	--

### 3.2.3 Results, Key Question 1a. Barriers/facilitators according to preventive service

USPSTF Clinical Preventive Service	Barrier/ Facilitator Factor Level	Physical Disability	Physical Disability	Cognitive Disability	Cognitive Disability	Sensory Disability	Sensory Disability	SMI Disability	SMI Disability	Multiple Disabilities	Multiple Disabilities
		<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>
Unhealthy alcohol use screening (n=2)	Environment	--	--	--	n=2	--	--	--	--	--	--
	Person	--	--	n=2	--	--	--	--	--	--	--
	Provider	--	--	n=1	n=1	--	--	--	--	--	--
	Healthcare system	--	--	n=1	--	--	--	--	--	--	--
	Accessibility- HCF	--	--	--	--	--	--	--	--	--	--
	Accessible communication	--	--	n=2	n=1	--	--	--	--	--	--
	Policy	--	--	--	--	--	--	--	--	--	--
Falls prevention in community- dwelling older adults (n=1)	Environment	--	--	--	--	--	--	--	--	--	--
	Person	--	--	--	n=1	--	--	--	--	--	--
	Provider	--	--	--	n=1	--	--	--	--	--	--
	Healthcare system	--	--	n=1	n=1	--	--	--	--	--	--
	Accessibility- HCF	--	--	--	--	--	--	--	--	--	--
	Accessible communication	--	--	--	--	--	--	--	--	--	--
	Policy	--	--	--	--	--	--	--	--	--	--
Healthy diet and physical activity for CVD prevention (n=1)	Environment	--	--	--	--	--	--	--	--	--	--
	Person	--	--	--	--	--	--	n=1	--	--	--
	Provider	--	--	--	--	--	--	--	--	--	--
	Healthcare system	--	--	--	--	--	--	n=1	n=1	--	--
	Accessibility- HCF	--	--	--	--	--	--	--	--	--	--
	Accessible communication	--	--	--	--	--	--	--	--	--	--
	Policy	--	--	--	--	--	--	--	--	--	--

### 3.2.3 Results, Key Question 1a. Barriers/facilitators according to preventive service

USPSTF Clinical Preventive Service	Barrier/ Facilitator Factor Level	Physical Disability	Physical Disability	Cognitive Disability	Cognitive Disability	Sensory Disability	Sensory Disability	SMI Disability	SMI Disability	Multiple Disabilities	Multiple Disabilities
		<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>	<i>Barrier</i>	<i>Facilitator</i>
Behavioral counseling to prevent STIs (n=3)	Environment	--	--	--	--	--	--	--	n=1	--	--
	Person	n=1	--	--	--	--	--	n=2	--	--	--
	Provider	--	--	--	--	--	--	n=2	n=2	--	--
	Healthcare system	--	--	--	--	--	--	n=1	n=1	--	--
	Accessibility- HCF	--	--	--	--	--	--	--	--	--	--
	Accessible communication	--	--	--	--	--	--	--	--	--	--
	Policy	--	--	--	--	--	--	--	--	--	--

Abbreviations: CVD=cardiovascular disease; HCF= healthcare facility; SMI=serious mental illness; STI=sexually transmitted infection; USPSTF=United States Preventive Services Task Force

### **3.2.4 Results, Key Question 1b. Barriers/facilitators according to type and/or severity of disability**

#### **3.2.4 Key Question 1b. How do these barriers/facilitators vary according to type and/or severity of disability?**

For most of the preventive services, either (1) the number of included studies and the number of reported barriers and/or facilitators was too small to allow for meaningful comments regarding variation by type of disability (screening for depression risk in adults; behavioral counselling to prevent sexually transmitted infections), or (2) the included studies pertained to only one general type of disability (screening for anxiety disorder in adults; screening for HIV infection; screening for unhealthy alcohol use; interventions for falls prevention in community-dwelling older adults; counselling for healthy diet and physical activity for CVD prevention). The following comments relate to breast, cervical, and colorectal cancer screening.

##### **3.2.4.1 Breast Cancer Screening**

Tables 5 to 9, in the section on Breast Cancer Screening above, present the reported barriers and facilitators according to general type of disability. Several general patterns across studies are notable. For example, lack of support/advocacy and transportation issues were reported for people with all types of disability. People with physical, cognitive/intellectual/developmental, sensory, or serious mental illness all reported distrust of the healthcare system, feeling vulnerable during mammography, and pain/discomfort with mammography as barriers to breast cancer screening. People with all types of disability also reported that providers' negative attitudes, lack of or insufficient insurance coverage, lack of explanation of the preventive service prior to the procedure, an inaccessible facility, and inaccessible mammography equipment are barriers to breast cancer screening. Providers' difficulty in communicating with people with physical, cognitive/intellectual/developmental, or sensory disability was reported as a barrier to the receipt of mammography. Certain barriers were only reported for people with cognitive/intellectual/developmental disability, including: barriers related to medical decision making such as a decision-making delegate's refusal, the person with cognitive/intellectual/developmental disability being unable to give informed consent, a provider not assessing the need for a decision-making delegate, and a caregiver lacking legal decision-making authority. Certain facilitators for screening mammography were reported for people with physical disability, cognitive/intellectual/developmental disability, sensory disability, and people with serious mental illness, including: being health conscious, feeling in control, having continuity of care, having a good rapport with their provider, reliable transportation, and supportive family/caregiver. Having a provider who explains the preventive service prior to the procedure and understanding barriers faced by people with disability were also facilitators reported by people with all types of disability. Allowing preparatory visits, the use of sedation during the procedure, using an alternative procedure, extra appointment time, and having a female provider were facilitators reported only by people with cognitive/intellectual/developmental disability and/or their caregivers.

##### **3.2.4.2 Cervical Cancer Screening**

Tables 12 to 15, in the section on Cervical Cancer Screening above, present the reported barriers and facilitators according to general type of disability. Several general patterns across studies are notable. There are many barriers and facilitators that are common across disability type, including: transportation issues; patients not understanding the screening process, experiencing discomfort with screening, or having fear and/or embarrassment around screening;

### **3.2.4 Results, Key Question 1b. Barriers/facilitators according to type and/or severity of disability**

whether or not providers were educated or knowledgeable about people with disabilities, listened to these patients, and had good rapport with them; whether providers used accessible communication, recommended screening to their patients with disabilities, and explained the screening procedure before undertaking it; and whether care was coordinated, appointments long enough, and screening reminders sent. Other barriers and facilitators were more specific to disability type. For example, inaccessible equipment and assistance with mobility and with dressing were reported only for patients with physical disabilities. Communication issues were more commonly reported for patients with cognitive disabilities, including patient literacy and providers having difficulty communicating or obtaining informed consent. A history of sexual assault, as well as providers' misconceptions about sexual activity and need for screening among patients with intellectual or developmental disabilities, were also reported. For patients with serious mental illness, specific barriers included psychiatric symptoms, and the clinic setting exacerbating these symptoms; a facilitator was screening performed in a familiar location.

#### **3.2.4.3 Colorectal Cancer Screening**

Tables 18 and 19, in the section on Colorectal Cancer Screening above, present the reported barriers and facilitators according to general type of disability. Several general patterns across studies are notable. For example, barriers related to transportation, lack of provider recommendation to receive screening, and fear and/or embarrassment were reported both for people with physical disabilities and people with serious mental illness; while barriers related to inaccessible equipment, inaccessible facility, and inaccessible test preparation process were reported only for people with physical disabilities. For people with physical disabilities, no facilitators were reported, while for people with serious mental illness studies reported multiple facilitators, such as care coordination and providers using accessible communication.

### **3.2.5 Results, Key Question 1c. Barriers/facilitators according to population characteristics**

#### **3.2.5 Key Question 1c. How do these barriers/facilitators vary according to characteristics such as: gender, race/ethnicity, economic status, LGBTQ+ status, or geographic location?**

No studies reported on variations in barriers or facilitators to the receipt of clinical preventive services according to characteristics such as: gender, race/ethnicity, economic status, LGBTQ+ status, or geographic location. For most of the preventive services, the number of included studies and the number of reported barriers and/or facilitators were too small to allow for meaningful comments regarding variation by these characteristics. The following comments relate to breast, cervical, and colorectal cancer screening.

##### **3.2.5.1 Breast Cancer Screening**

No studies reported on variations in barriers or facilitators to the receipt of breast cancer screening according to characteristics such as: gender, race/ethnicity, economic status, LGBTQ+ status, or geographic location. Nor did a sufficient number of studies report on these characteristics within the study populations to allow for meaningful general comparisons across studies. However, one study in women with physical, sensory, or any combination of physical, hearing, and/or visual disability reported that women of Black and other race/ethnicity were more likely to report needing additional staff assistance with paperwork and during the appointment than white women, as a facilitator to receive mammography.<sup>66</sup> The study also reported that Black women were more likely to report longer appointment time as a facilitator than white and other race/ethnicity women.<sup>66</sup> Compared with White women, those of other races/ethnicities were more likely to report having an oral description of the procedure as a facilitator.<sup>66</sup> In a study targeting Native American women in rural and urban settings,<sup>54</sup> distrust of allopathic medicine was mentioned as a barrier while studies in other race/ethnicity groups only pointed to general mistrust of the healthcare system. Nine of the included 36 studies were conducted in urban and rural settings,<sup>54,60,61,64,66,70-72,74</sup> and four studies were conducted in urban setting.<sup>59,79,82,88</sup> Six of the nine studies in mixed settings did not mention any difference between in reported barriers and facilitators,<sup>61,64,66,70,72,74</sup> while two studies reported similar barriers and facilitators between rural and urban settings.<sup>60,71</sup> Reported barriers and facilitators were generally similar between studies conducted only in an urban setting and other studies.<sup>59,79,82,88</sup> In the study in Native American women with cognitive/intellectual/developmental disability, reported barriers and facilitators were generally similar between rural and urban settings, except for rural women reported longer travel distance as a barrier that was not mentioned by women in urban setting.<sup>54</sup>

##### **3.2.5.2 Cervical Cancer Screening**

No studies reported on variations in barriers or facilitators to the receipt of cervical cancer screening according to characteristics such as: gender, race/ethnicity, economic status, LGBTQ+ status, or geographic location. However, some studies did report on these characteristics within the included study populations, and we note several general patterns across studies. Two of the 19 studies included younger age groups, with the largest groups of patients in each study approximately 20 to 30 years old;<sup>56,85</sup> another two studies included older patients, with the largest groups in their mid-40's to mid-60's.<sup>60,61</sup> The only barriers or facilitators in common between the studies of older and younger patients were fear and/or embarrassment (barrier) and rapport with the provider (facilitator). Distrusting the healthcare system and lacking insurance

### **3.2.5 Results, Key Question 1c. Barriers/facilitators according to population characteristics**

were reported barriers for younger patients, as was the facilitator of providers listening to people with disabilities; there were many barriers/facilitators reported for older patients, including inaccessible facility, transportation issues, care coordination, and not understanding the screening process.

One study, described above for breast cancer screening, included only Native American women with disabilities, 67 percent of whom lived in a rural setting.<sup>54</sup> Comparing this study to two studies of primarily White patients<sup>61,74</sup> showed several barriers or facilitators in common: transportation issues, not understanding the screening process, rapport with provider, and provider using accessible communication. Barriers and facilitators that differed between the groups included, in Native American women, lacking insurance or internet, having a supportive family or caregiver, and distrusting the healthcare system; and in the studies with predominantly White women, care coordination, fear and/or embarrassment, and lack of motivation.

Comparing the study of Native American women in largely rural settings with three studies in which about 90 percent of people with disabilities lived in urban or other nonrural settings,<sup>60,74,92</sup> an inaccessible facility and misconceptions about sexual activity and need for screening were the only barriers or facilitators in common. Barriers or facilitators reported in the studies of nonrural people with disabilities, but not in primarily rural Native American women, included: patient and provider time constraints, lack of rapport with the provider, and the provider not recommending screening.

#### **3.2.5.3 Colorectal Cancer Screening**

No studies reported on variations in barriers or facilitators to the receipt of colorectal cancer screening according to characteristics such as: gender, race/ethnicity, economic status, LGBTQ+ status, or geographic location. However, some studies did report on these characteristics within the included study populations, and we note a general pattern across studies. Two of the included 6 studies enrolled primarily female patients (87% and 100%), and 4 studies had more balanced gender ratios. Transportation issues, fear and/or embarrassment, and not understanding the screening process were common barriers across studies, while other barriers and facilitators were present more in one group of studies than the other; for example, lack of provider recommendation was reported in the mixed-gender studies but not in those primarily of female patients.

### 3.3 Results, Key Question 2. Effectiveness of interventions

#### 3.3 Key Question 2. What is the effectiveness of interventions to improve the receipt of clinical preventive services among people with disabilities?

##### 3.3.1 Key Points

- Sixteen studies reported on the effectiveness of interventions to improve the receipt of clinical preventive services for people with disabilities, including 8 studies of interventions directed at people with disabilities, two studies of interventions for clinicians, four studies of multicomponent interventions targeting both people with disabilities and clinicians, and two studies of health system-level interventions.
- Studies included people with physical disabilities (n=3), cognitive/intellectual/developmental disabilities (n=8), sensory disabilities (n=4), and serious mental illness (n=1).
- Eight studies assessed interventions to increase rates of breast cancer screening, including five RCTs that found educational and health advocacy interventions associated with increased screening in people with disabilities, although risk estimates were not consistently statistically significant.
- Cervical cancer screening rates were generally increased following general education and health advocacy interventions versus usual care or no intervention based on nine studies, including four RCTs. One nonrandomized trial of an intervention specifically designed to increase cervical cancer screening rates in women with sensory disability found a large but imprecise effect on screening rates (RR 23, 95% CI, 3.18 to 166).
- Evidence from one before-after study of an educational intervention for people with cognitive/ intellectual/ developmental disabilities reported promising results, but only reported screening intent rather than actual screening uptake.
- Three RCTs and one cross-sectional study did not find interventions aimed at general health improvement to be associated with a difference in the proportion of people with disabilities who underwent blood pressure checks when compared with usual care or no intervention.
- An uncontrolled cohort study of a weight loss and health improvement intervention to reduce obesity-related morbidity, modified for people with cognitive disability, was associated with significant changes in BMI and exercise frequency at 9-week followup.
- Evidence on interventions to increase uptake of other clinical preventive services including depression screening, prediabetes/type 2 diabetes screening, and falls prevention is limited to one study each, with no clear effect of interventions for any preventive service.

##### 3.3.2 Summary of Findings

We identified 16 studies<sup>87,97,107-120</sup> that reported on the effectiveness of interventions to improve the receipt of clinical preventive services for people with disabilities. These included seven RCTs,<sup>107-113</sup> seven NRSIs,<sup>87,97,114-118</sup> and two cross-sectional studies.<sup>119,120</sup> Studies included people with physical disabilities (n=3),<sup>87,110,113</sup> cognitive/intellectual/developmental disabilities (n=8),<sup>111,112,114-116,118-120</sup> sensory disabilities (n=4),<sup>97,108,109,117</sup> and serious mental illness (n=1).<sup>107</sup> Studies assessed interventions to increase rates of breast cancer screening (n=8),<sup>87,107,108,111-113,117,120</sup> cervical cancer screening (n=9),<sup>107,109,111-114,117,119,120</sup> colorectal cancer screening



### 3.3 Results, Key Question 2. Effectiveness of interventions

(n=3),<sup>107,115,116</sup> depression screening in adults (n=1),<sup>97</sup> screening for hypertension (n=4),<sup>107,111,112,120</sup> screening for prediabetes/type 2 diabetes (n=1),<sup>120</sup> prevention of falls (n=1),<sup>110</sup> and weight-loss to prevent obesity (n=3);<sup>111,112,118</sup> seven of the studies assessed multiple clinical preventive services.<sup>107,111-113,117,119,120</sup> All of the clinical preventive services were targeted towards adults; we identified no studies conducted in children or adolescents.

Intervention characteristics are summarized in Table 31. Interventions were directed at people with disabilities in eight studies,<sup>107-110,113,114,116,118</sup> interventions for clinicians in two studies,<sup>97,119</sup> and multicomponent interventions targeting both people with disabilities and clinicians in four studies.<sup>111,112,115,120</sup> Two studies assessed interventions aimed at system-level barriers.<sup>87,117</sup> Among the studies, the duration of treatment ranged widely from a single session to 1 year. In 14 of the studies, interventions were focused on reducing barriers to preventive care uptake through appropriate education and/or increasing awareness for patients, caregivers, and or clinicians.<sup>97,107-116,118-120</sup> Two other studies assessed interventions aimed at removing system-level barriers: one study assessed how provision of an American Sign Language interpreter in primary care clinics affected preventive care uptake by D/deaf people,<sup>117</sup> and one study aimed to remove barriers to breast cancer screening for women with disabilities through an “open-door” mammography clinic.<sup>87</sup>

As described in the Methods, risk of bias was assessed using separate criteria for the RCTs and the NRSIs. Among the seven RCTs, two<sup>111,112</sup> were judged to have low risk of bias. The remaining five RCTs<sup>107-110,113</sup> were rated moderate risk of bias; common methodological limitations included unclear randomization and allocation concealment, and unclear or lack of blinding of outcome assessors. The NRSIs comprised a variety of study designs, including cohort studies, before-after studies, and case-control studies. One NRSI had few limitations and was judged to have a low risk of bias.<sup>114</sup> The remaining six NRSIs were rated moderate risk of bias, primarily due to missing details about baseline characteristics of study participants, loss to followup, and maintenance of comparable intervention groups.<sup>87,97,115-118</sup> Risk of bias was not assessed for the two included cross-sectional studies.<sup>119,120</sup>

### 3.3 Results, Key Question 2. Effectiveness of interventions

**Table 31. Characteristics of interventions to improve the receipt of clinical preventive services among people with disabilities**

Author, Year Study Design N <sup>a</sup>	Disability Type(s) Addressed	Setting Duration of Intervention	Who Delivered the Intervention	Intervention Target	Intervention Name and/or Key Components
Bartels 2014 <sup>107</sup> RCT N=183	Serious mental illness	Community  1 year	Therapist (social skills training) and nurse (preventive care) embedded in community mental health service	General preventive care	HOPES <ul style="list-style-type: none"> <li>• Weekly group social skills training and bimonthly community trips to practice social skills</li> <li>• Monthly meetings with a nurse who evaluated participants preventive care needs and facilitated screenings and primary care coordination</li> </ul>
Biswas 2005 <sup>114</sup> NRSI N=160	Cognitive/IDD	Community  Single session	Nurse from community learning disability team	Cervical cancer screening	One-on-one counseling using a customized toolkit developed by Learning Disability Nurses
Bowler 2015 <sup>115</sup> NRSI N=193	Cognitive/IDD	Community  Single session	Nurse from community learning disability team	Colorectal cancer screening	Patient- and clinician-targeted intervention <ul style="list-style-type: none"> <li>• “Easy read” screening letter for people with cognitive/IDD aimed at explaining colorectal cancer screening process</li> <li>• Training pack for clinical staff to designed to decrease staff discomfort surrounding discussion of colorectal cancer screening for people with cognitive/IDD</li> </ul>
Chauhan 2010 <sup>119</sup> Cross- sectional N=651	Cognitive/IDD	General practice  NR (unclear if single or multiple clinic visits)	Nurse or physician (at the discretion of the general practice)	General preventive care	Clinic use of routine health check (Cardiff Health Check), modified to accurately identify uptake in people with cognitive/IDD
Cumberland 2018 <sup>108,121</sup> RCT N=209	Sensory	Community  Single session	Deaf community members with health education experience, trained by research team members	Breast cancer screening	Breast cancer education program <ul style="list-style-type: none"> <li>• Culturally and linguistically sensitive education program emphasizing individual level Health Behavior Framework constructs</li> <li>• Content delivered in small group sessions via a brochure and specially produced video</li> </ul>
Durbin 2019 <sup>120,122</sup> Cross- sectional N=276	Cognitive/IDD	Multidisciplinary, primary care- based clinic (Family Health Team)  Single clinic visit	Family Health Team members	General preventive care	Health Check <ul style="list-style-type: none"> <li>• Comprehensive health review for patients</li> <li>• Staff support via point-of-care tools and education specific to primary care treatment for people with cognitive/IDD</li> </ul>

### 3.3 Results, Key Question 2. Effectiveness of interventions

Author, Year Study Design N <sup>a</sup>	Disability Type(s) Addressed	Setting Duration of Intervention	Who Delivered the Intervention	Intervention Target	Intervention Name and/or Key Components
Esmeray 2022 <sup>109</sup> RCT N=156	Sensory	Community  Single session	Unclear	Cervical cancer screening	Educational program <ul style="list-style-type: none"> <li>• Face-to-face program describing female anatomy, cervical cancer risk factors, incidence and symptoms</li> <li>• Take home brochure and video reinforcing materials taught during face-to-face session</li> <li>• Information card to be used by study participants to facilitate screening and to prevent communication difficulties when presenting for screening</li> </ul>
Gray 2021 <sup>116</sup> NRSI N=109	Cognitive/IDD	Community  Single session	Peer educator	Colorectal cancer screening	Peer-led interactive educational program, based on health belief model, on bowel health and colorectal cancer screening awareness
Kannan 2019 <sup>110</sup> RCT N=30	Physical	Online  8 weeks	NA (online, self-directed program)	Falls prevention	Free From Falls Online <ul style="list-style-type: none"> <li>• Web-based fall prevention program teaching self-management strategies to prevent falls, includes weekly webinar and supplementary downloadable materials</li> <li>• At-home video exercise program</li> </ul>
Lennox 2007 <sup>111</sup> RCT N=453	Cognitive/IDD	Home and primary care  Single session	Collaborative effort between patient, caregiver, and general physician	General preventive care	CHAP booklet <ul style="list-style-type: none"> <li>• Medical history completed by patient's caregiver</li> <li>• Assessment of patient history and targeted examination completed by general practitioner</li> <li>• Collaborative health action plan developed by caregiver and general practitioner</li> </ul>
Lennox 2010 <sup>112</sup> RCT N=242	Cognitive/IDD	Home and primary care  Single session (CHAP) and 1 year (ASK)	Collaborative effort between patient, caregiver, and general physician	General preventive care	CHAP booklet <ul style="list-style-type: none"> <li>• see Lennox 2007</li> </ul> ASK health diary <ul style="list-style-type: none"> <li>• Designed for ongoing use in all medical consultations</li> <li>• Includes 4 sections: "All About Me" and "Health Advocacy Tips" for patients and caregivers; "For The Doctor" and "Medical Records" for clinical staff</li> </ul>
MacKinney 1995 <sup>117</sup> NRSI N=175	Sensory	Community- based primary care clinic  NR (unclear if single or multiple clinic visits)	Trained ASL interpreter	General preventive care	Primary care provision of in-clinic ASL interpreters

### 3.3 Results, Key Question 2. Effectiveness of interventions

Author, Year Study Design N <sup>a</sup>	Disability Type(s) Addressed	Setting Duration of Intervention	Who Delivered the Intervention	Intervention Target	Intervention Name and/or Key Components
Magasi 1995 <sup>87</sup> NRSI N=16 Year 1; N=31 Year 2	Physical	Community  Single session	Community, research, and clinical collaborative team	Breast cancer screening	ScreenABLE Saturday Walk-in mammogram for women with disabilities, provided regardless of insurance and documentation status
Mann 2006 <sup>118</sup> NRSI N=192	Cognitive/IDD	Community  8 weeks	Community disability service provider staff, with training and support from study researchers	Weight loss to prevent obesity	Modified Steps to Your Health <ul style="list-style-type: none"> <li>• Health promotion program delivered using simplified language, targeting nutrition, exercise, stress reduction, communication, motivation to change, and relapse prevention</li> <li>• Classes include participatory activities and discussions.</li> </ul>
Nollett 2020 <sup>97</sup> NRSI N=40	Sensory	Specialty care  Single session (included an online lecture and face-to-face workshop)	Low Vision Service Wales clinical team	Depression screening	Low Vision Service Wales training program for vision care providers (ophthalmologists, optometrists, opticians) to deliver a 2-question depression screening to low vision patients
Peterson 2012 <sup>113</sup> RCT N=211	Physical	Community  6 months	Women with mobility disabilities	Breast and cervical cancer screening	PATHS <ul style="list-style-type: none"> <li>• Small-group format and monthly structured telephone support</li> <li>• Components include education about screening benefits, procedures, and recommendations; overcoming barriers to screening; building skills for communicating with physicians; setting goals; and initiating change</li> </ul>

<sup>a</sup>Represents total enrolled population

Abbreviations: ASK = advocacy skills training; ASL = American Sign Language; CHAP = Comprehensive Health Assessment Program; HOPES = Helping Older People Experience Success; IDD = intellectual and/or developmental disabilities; NA = not applicable; NR = not reported; NRSI = nonrandomized study of interventions; PATHS = Promoting Access to Health Services

### 3.3 Results, Key Question 2. Effectiveness of interventions

#### 3.3.2.1 Breast Cancer Screening

Five RCTs,<sup>107,108,111-113</sup> two NRSIs,<sup>87,117</sup> and one cross-sectional study<sup>120</sup> assessed interventions to increase rates of breast cancer screening (Table 32).

##### 3.3.2.1.1 Physical Disability

One RCT,<sup>113</sup> designed to increase breast and cervical cancer screening, compared the effect of an educational and behavioral intervention with usual care on mammogram uptake in 125 women with physical disability (mean age 52 years) who had not undergone a mammogram in the 2 years preceding the study. Most women in the study used a mobility aid (78%), and had a co-occurring cognitive (56%) and/or sensory (14%) disability. Over half the population (54%) had the equivalent of a high school diploma or less, 69 percent had an annual income of less than \$10,000 (equivalent to \$13,690 in 2024),<sup>123</sup> and 9 percent were employed. The population was predominantly White race (66%), followed by Black (14%) and Hispanic (11%) women. The intervention group received Promoting Access to Health Services (PATHS), which included a small-group educational workshop on the importance of preventive services followed by structured telephone support for 6 months, while the control group received general health promotion materials. After 6-month followup, 49 percent (29/59) of women who received the PATHS intervention and 42 percent of controls (28/66) reported receipt of a mammogram, resulting in a small intervention effect that was not statistically significant (RR 1.16, 95% CI, 0.79 to 1.70). Results of this study are limited due to the relatively short duration of followup and a high attrition rate (26%) in the intervention group.

The only other evidence on reducing barriers to breast cancer screening for women with physical disabilities comes from a noncomparative study that described the development and initial implementation of a community-based intervention that provided barrier-free mammograms to women with disabilities (ScreenABLE Saturday) to increase breast cancer screening.<sup>87</sup> Similar mammogram uptake was reported during the first (19%) and second year of implementation (16%), although overall ScreenABLE Saturday attendance increased from 16 participants in the first year to 31 participants in the second year.

##### 3.3.2.1.2 Cognitive/Intellectual/Developmental Disability

Two RCTs<sup>111,112</sup> and one cross-sectional study<sup>120</sup> reported mammography uptake in women with cognitive, intellectual, and/or developmental disabilities. The interventions in all three studies were targeted at general health promotion that included mammography, but none focused specifically on breast cancer screening.

The most robust evidence comes from a cluster RCT comparing use of a Comprehensive Health Assessment Program (CHAP) versus usual care.<sup>111</sup> The study enrolled a total of 453 participants. Of these, 186 comprised the subgroup of women who met criteria for breast cancer screening; patient characteristics for this subgroup were not reported. The CHAP intervention consisted of a booklet designed for use by patients/caregivers and clinicians. Prior to a clinic visit, patients/caregivers completed a medical history section of the booklet. At the clinic visit, the booklet was used by the physician to review history, conduct a targeted exam, and develop a health action plan. After 1-year followup, the proportion of woman who received a mammogram was 15 percent (13/89) in the CHAP group versus 4 percent (4/97) in the usual care group (RR 3.5, 95% CI, 1.1 to 1.2). A second, smaller cluster RCT<sup>112</sup> conducted by the same research group compared CHAP with a health diary designed for ongoing use (Advocacy Skills Training [ASK]) and usual care. The study employed a factorial design, comparing CHAP versus no

### 3.3 Results, Key Question 2. Effectiveness of interventions

CHAP and ASK versus no ASK, but did not directly compare either intervention alone to usual care. Although the study enrolled 272 participants, only 14 women met criteria for mammography. Of these 14 women, two underwent a mammogram, resulting in no differences between the comparison groups. The third study (n=40) used a cross-sectional design and compared women who underwent a comprehensive health review (Health Check) with those who had no comprehensive review. The study found the Health Check associated with a small, nonsignificant increase in the likelihood of receiving a mammogram (63% [17/27] vs. 54% [7/13]; adjusted OR 1.3 (0.3 to 5.1).

#### 3.3.2.1.3 Sensory Disability

One RCT<sup>108</sup> and one case-control study<sup>117</sup> reported on interventions to increase breast cancer screening in women with sensory disability; both studies focused on D/deaf women.

The RCT enrolled 182 women, 73 percent of whom had no more than a high-school level of education. The majority (68%) of the population had an annual income  $\leq$ \$20,000 (equivalent to \$25,039 in 2024),<sup>123</sup> 9 percent reported working either full- or part-time, and 6 percent were uninsured. Race/ethnicity of the study participants was reported as 52 percent White, 22 percent Hispanic, 12 percent Black, 6 percent Asian or Pacific Islander, and 8 percent multiracial. Women enrolled in the intervention group (n=90) received a specialized education program specifically developed to be culturally and linguistically relevant for the study population. Educational content was delivered through a brochure and freely available video, and focused on potential knowledge gaps, patient-provider communication, health beliefs, and barriers/supports to obtaining breast cancer screening. The control group (n=92) included women who did not receive the specialized education program. After 1-year followup, rates of mammography were found to be similar in both the intervention (66% [58/88]) and control (63% [52/83]) groups, resulting in nonsignificant risk estimate (RR 1.05, 95% CI, 0.84 to 1.32).

The case-control study focused on how provision of an American Sign Language (ASL) interpreter during clinical visits affected breast cancer screening uptake.<sup>117</sup> The study found that having an ASL interpreter available was associated with a large increase in screening likelihood (OR 6.0, 95% CI, 1.1 to 37.0). Although this result is promising, the study has numerous methodological limitations which limit interpretability of this finding. The controls in the study were described as “friends” of the cases who were referred to the study by their case friend, and no attempt was made to adjust for any baseline confounding factors. As a result, there were numerous significant differences between groups at baseline, most notably cases were more likely to have visited a doctor in the year preceding the study compared to the controls (5.4 vs. 3.7 visits/year;  $p < 0.001$ ), which potentially skewed the results in favor of the cases. In addition, 42 women were reported as being eligible for breast cancer screening, but the number of these who were cases and controls and the number who underwent screening is neither reported nor calculable.

#### 3.3.2.1.4 Serious Mental Illness

One RCT<sup>107</sup> compared Helping Older People Experience Success (HOPES) with usual care in people with serious mental illness. HOPES was a 1-year multicomponent intervention that included weekly small group social skills training and monthly preventive health meetings with a nurse, who worked with participants to set preventive care goals and to facilitate screening. The study enrolled 183 adults aged 50 years and older with schizophrenia, schizoaffective disorder, bipolar disorder, or major depressive disorder according to DSM-IV criteria. The majority of the

### 3.3 Results, Key Question 2. Effectiveness of interventions

sample was White (85%) and non-Hispanic (93%). Of these, 103 women met criteria for breast cancer screening. The study found women randomized to HOPES significantly more likely than those in the usual care group to have had at least one mammogram during the 3-year followup (85% [45/53] vs. 67% [34/51]: RR 1.27, 95% CI, 1.02 to 1.59).

**Table 32. Studies of interventions to improve the receipt of breast cancer screening**

<b>Disability</b>	<b>Author, Year Study Design Duration of Followup</b>	<b>Sample Size<sup>a</sup> Screening Indication</b>	<b>Intervention Comparator</b>	<b>Results</b>
<b>Physical disability</b>	Peterson, 2012 <sup>113</sup> RCT 6 months	N=125 Mean age: 52 years Screening conducted in women not current on USPSTF (2007) recommended screening	PATHS vs. General health promotion materials	Mammogram conducted: 49% (29/59) vs. 42% (28/66); RR 1.16 (95% CI, 0.79 to 1.70)
	Magasi, 2019 <sup>87</sup> Descriptive 2 years	N=47 Mean age NR Screening indication NR	ScreenABLE Saturday (walk-in mammogram service) vs. NA	Mammogram conducted as part of ScreenABLE Saturday: Year 1: 19% (3/16) Year 2: 16% (5/31)
<b>Cognitive/intellectual/ developmental disability</b>	Lennox, 2007 <sup>111</sup> Cluster RCT 1 year	N=186 Mean age: 39 years Screening conducted where “clinically indicated and according to national guidelines”	CHAP vs. Usual care	Mammogram conducted: 15% (13/89) vs. 4% (4/97); RR 3.5 (95% CI, 1.1 to 12)
	Lennox, 2010 <sup>112</sup> Cluster RCT 1 year	N=14 Mean age: 36 years Screening conducted in women in “the recommended age range”	CHAP vs. No CHAP <sup>b</sup>	Mammogram conducted: 0% (0/8) vs. 33% (2/6); p=0.20 (adjusted OR not reported)
	Lennox, 2010 <sup>112</sup> Cluster RCT 1 year	N=14 Mean age: 36 years Screening conducted in women in “the recommended age range”	ASK vs. No ASK <sup>c</sup>	Mammogram conducted: 13% (1/8) vs. 17% (1/6); adjusted OR 1.1 (95% CI, 0.1 to 11.3)
	Durbin, 2019 <sup>120</sup> Cross-sectional NA	N=40 Mean age: NR Screening conducted in women age 50 to 74 years according to Canadian guidelines (2011)	Health Check vs. No Health Check	Mammogram conducted: 63% (17/27) vs. 54% (7/13); adjusted OR 1.3 (0.3 to 5.1)
<b>Sensory disability</b>	Cumberland, 2018 <sup>108</sup> RCT 1 year	N=182 Mean age: NR; 33% <50 years; 23% 50-59 years; 30% 60-75 years; 15% >75 years Screening conducted in all enrolled women (including those >75 years)	Specialized education program vs. No specialized education program	Mammogram conducted: 66% (58/88) vs. 63% (52/83); RR 1.05 (95% CI, 0.84 to 1.32)  Change in screening from baseline: 20% (18/88) vs. 27% (22/83); RR 0.77 (95% CI, 0.45 to 1.33)

### 3.3 Results, Key Question 2. Effectiveness of interventions

Disability	Author, Year Study Design Duration of Followup	Sample Size <sup>a</sup> Screening Indication	Intervention Comparator	Results
	MacKinney, 1995 <sup>117</sup> Case-control Followup NR	N=42 Mean age: 46 years Screening indication NR	Cases: enrolled in primary care which provided ASL interpreters vs. Controls: Controls: no primary care provision of ASL interpreters	Mammogram conducted: 87% (n/N NR) vs. 53% (n/N NR); OR 6.0 (95% CI, 1.1 to 37)
Serious mental illness	Bartels, 2014 <sup>107</sup> RCT 3 years	N=104 Mean age: 60 years Screening conducted according to USPSTF (2013) recommendations	HOPES vs. Usual care	Mammogram conducted: 85% (45/53) vs. 67% (34/51); RR 1.27 (95% CI, 1.02 to 1.59)

Abbreviations: ASL = American Sign Language; ASK = Advocacy Skills Training; CHAP = Comprehensive Health Assessment Program; CI = confidence interval; HOPES = Helping Older People Experience Success; NA = not applicable; NNT = number needed to treat; NR = not reported; OR = odds ratio; PATHS = Promoting Access to Health Services; RCT = randomized controlled trial; RR = relative risk; USPSTF = United States Preventive Services Task Force

<sup>a</sup> Sample size for breast cancer screening only; several studies assessed multiple clinical preventive services. Mean age was reported for entire population (not limited to breast cancer screening population).

<sup>b</sup> The CHAP group included people randomized to CHAP or CHAP + ASK; The No CHAP group included those randomized to ASK or usual care

<sup>c</sup> The ASK group included people randomized to ASK or CHAP + ASK; The No ASK group included those randomized to CHAP or usual care

#### 3.3.2.2 Cervical Cancer Screening

Nine studies, including four RCTs,<sup>107,111-113</sup> three NRSIs,<sup>109,114,117</sup> and two cross-sectional studies<sup>119,120</sup> assessed interventions to increase rates of cervical cancer screening, six<sup>107,111-113,117,120</sup> of which are discussed in the breast cancer section, above (Table 33).

##### 3.3.2.2.1 Physical Disability

The RCT described in Section 3.3.2.1.1 comparing the educational workshop and telephone support intervention PATHS with general health promotion included 71 women with physical disability who were eligible for cervical cancer screening.<sup>113</sup> At 6-month followup, the rate of Pap testing was 61 percent (25/41) in the PATHS group and 27 percent (8/30) in the control group (RR 2.20, 95% CI, 1.15 to 4.19).

##### 3.3.2.2.2 Cognitive/Intellectual/Developmental Disability

Two RCTs,<sup>111,112</sup> one before-after study,<sup>114</sup> and two cross-sectional studies<sup>119,120</sup> reported on interventions to increase cervical cancer screening rates in women with cognitive, intellectual, and/or developmental disabilities.

One RCT, described in Section 3.3.2.1.2, compared CHAP versus usual care.<sup>111</sup> The study included 200 women eligible for cervical cancer screening. At 1-year followup, screening uptake was fairly low in both the intervention (16% [13/93]) and control (2% (2/107) groups, resulting in a large but imprecise risk estimate favoring CHAP (RR 7.9, 95% CI, 1.8 to 35). The second RCT, conducted by the same researchers, compared CHAP with no CHAP and ASK with no ASK. As with the other RCT, screening uptake at 1 year was low across all groups. For CHAP versus no CHAP, rates of Pap testing were 6 percent (3/48) and 8 percent (4/56), with no clear



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difference between groups (adjusted OR 0.9, 95% CI, 0.2 to 4.1). When comparing ASK with no ASK, cervical cancer screening rates were significantly lower in the ASK group (2% [1/49] vs. 12% [6/55]; adjusted OR 0.2, 95% CI, 0.0 to 1.0). Due to the factorial design used in this study, interpretation of these results is difficult, as both control groups included some people who had received an active intervention.

The effect of one-on-one counseling designed to increase cervical cancer screening uptake was assessed in a before-after study of 160 women with learning disabilities.<sup>114</sup> Prior to the intervention, 16 percent (26/160) women reported a prior Pap test, which increased to 22 percent (35/160) following the intervention (RR 1.35, 95% CI, 0.85 to 2.13). An additional eight women (43/160) had provided consent and intended to undergo cervical cancer screening following the counseling intervention, but were unable to physically complete the screening.

Two cross-sectional studies assessed the effect of an enhanced health check on cervical cancer screening rates.<sup>119,120</sup> There were some differences between the health check interventions. One study involved the addition of health check measures relevant to people with intellectual disabilities (e.g., assessment of feeding, bladder, and bowel function) to standard health check measures during clinic visits.<sup>119</sup> That study found that women who underwent the modified health check were more likely to have undergone cervical cancer screening than women who had standard health checks (86% [24/28 vs. 56% [95/169]; RR 1.52, 95% CI, 1.25 to 1.87). The study was conducted in the UK, where general practice clinics have a financial incentive to conduct health checks through the National Health Service Quality and Outcomes Framework,<sup>124</sup> which may help to explain the relatively high screening uptake in both groups compared to those in other studies. In the second study,<sup>120</sup> people with cognitive/IDD were proactively identified and solicited by participating clinical practices to attend a health check, and clinical staff were supported with additional training and education to help them effectively work with people with cognitive/IDD. That study found similar rates for screening uptake in the health check (34% [23/68]) and control (32% [16/50]) groups (adjusted OR 1.0, 95% CI, 0.5 to 2.2).

#### 3.3.2.2.3 Sensory Disability

One nonrandomized trial<sup>109</sup> and one case-control study<sup>117</sup> assessed interventions to increase cervical cancer screening rates in women with sensory disability; both studies included women who were deaf and/or hearing impaired. The nonrandomized trial (N=156) compared an educational intervention with usual care (no specialized education). The educational intervention was designed specifically for women with hearing impairments, with the intent of increasing their knowledge about cervical health, Pap testing, and the need for screening. The education piece included both face-to-face training, and a take-home brochure and video. To potentially ease communication difficulties, following the education piece the intervention group also received a card that study participants could bring to their Pap test appointment that included their personal information and hearing status. The study found the educational intervention associated with a large but imprecise effect on cervical cancer screening when compared with usual care (29.5% [23/78] vs. 1.3% [1/78]; RR 23, 95% CI, 3.18 to 166). The case-control study involved provision of ASL interpreters during clinic visits.<sup>117</sup> Although the study found that having an interpreter available was associated with higher rates of cervical cancer screening (90% vs. 72%; OR 3.5, 95% CI, 1.0 to 13), the study had numerous methodological limitations (described in Section 3.3.2.1.3) and this finding should be interpreted cautiously.

### 3.3 Results, Key Question 2. Effectiveness of interventions

#### 3.3.2.2.4 Serious Mental Illness

One RCT<sup>107</sup> that included 104 women with serious mental illness who were eligible for cervical cancer screening compared weekly social skills training plus monthly preventive care meetings (HOPES) with usual care (see Section 3.3.2.1.4). At 3-year followup, women in the HOPES group were more likely to have undergone cervical cancer screening compared with those randomized to usual care (77% [41/53] vs. 49% [25/51], RR 1.58, 95% CI, 1.15 to 2.16).

**Table 33. Studies of interventions to improve the receipt of cervical cancer screening**

<b>Disability</b>	<b>Author, Year Study Design Duration of Followup</b>	<b>Sample Size<sup>a</sup> Mean Age</b>	<b>Intervention Comparator</b>	<b>Results</b>
<b>Physical disability</b>	Peterson, 2012 <sup>113</sup> RCT 6 months	N=71 Mean age: 52 years Screening conducted in women not current on USPSTF (2007) recommended screening	PATHS vs. General health promotion materials	Pap test conducted: 61% (25/41) vs. 27% (8/30); RR 2.20 (95% CI, 1.15 to 4.19)
<b>Cognitive/intellectual/ developmental disability</b>	Lennox, 2007 <sup>111</sup> Cluster RCT 1 year	N=200 Mean age: 39 years Screening conducted where "clinically indicated and according to national guidelines"	CHAP vs. Usual care	Pap test conducted: 16% (13/93) vs. 2% (2/107); RR 7.9 (95% CI, 1.8 to 35)
	Lennox, 2010 <sup>112</sup> Cluster RCT 1 year	N=104 Mean age: 36 years Screening conducted in women in "the recommended age range"	CHAP vs. No CHAP <sup>b</sup>	Pap test conducted: 6% (3/48) vs. 8% (4/56); adjusted OR 0.9 (95% CI, 0.2 to 4.1)
	Lennox, 2010 <sup>112</sup> Cluster RCT 1 year	N=104 Mean age: 36 years Screening conducted in women in "the recommended age range"	ASK vs. No ASK <sup>c</sup>	Pap test conducted: 2% (1/49) vs. 12% (6/55); adjusted OR 0.2 (95% CI, 0.0 to 1.0)
	Biswas 2005 <sup>114</sup> Before-after	N=160 Mean age NR Screening conducted according to national guidelines (UK, 2000)	One-on-One Counseling, After vs. One-on-One Counseling, Before	Pap test conducted: 22% (35/160) vs. 16% (26/160) vs.; RR 1.35 (95% CI, 0.85 to 2.13)  Pap test intended <sup>d</sup> : 27% (43/160) vs. 16% (26/160); RR 1.65 (95% CI, 1.07 to 2.55)
	Chauhan 2010 <sup>119</sup> Cross-sectional NA	N=197 Mean age: 52 years Screening conducted to according to UK Quality and Outcomes Framework health check measures	Modified Cardiff Health Check vs. No Modified Cardiff Health Check	Pap test conducted: 86% (24/28) vs. 56% (95/169); RR 1.52 (95% CI, 1.25 to 1.87)

### 3.3 Results, Key Question 2. Effectiveness of interventions

Disability	Author, Year Study Design Duration of Followup	Sample Size <sup>a</sup> Mean Age	Intervention Comparator	Results
	Durbin, 2019 <sup>120</sup> Cross-sectional NA	N=118 Mean age: NR Screening conducted in women age 21 to 69 years according to Canadian guidelines (2011)	Health Check vs. No Health Check	Pap test conducted: 34% (23/68) vs. 32% (16/50); adjusted OR 1.0 (95% CI, 0.5 to 2.2)
Sensory disability	Esmeray 2022 <sup>109</sup> Nonrandomized trial	N=156 Mean age: 50 years Screening indication NR	Educational intervention vs. Waitlist	Pap test conducted: 29.5% (23/78) vs. 1.3% (1/78); RR 23 (95% CI, 3.18 to 166)
	MacKinney, 1995 <sup>117</sup> Case-control Followup NR	N=93 Mean age: 46 years Screening indication NR	Cases: enrolled in primary care which provided ASL interpreters vs. Controls: Controls: no primary care provision of ASL interpreters	Pap test conducted: 90% (n/N NR) vs. 72% (n/N NR); OR 3.5 (95% CI, 1.0 to 13)
Serious mental illness	Bartels, 2014 <sup>107</sup> RCT 3 years	N=104 Mean age: 60 years Screening conducted according to USPSTF (2013) recommendations	HOPES vs. Usual care	Pap test conducted: 77% (41/53) vs. 49% (25/51); RR 1.58 (95% CI, 1.15 to 2.16)

Abbreviations: ASL = American Sign Language; ASK = Advocacy Skills Training; CHAP = Comprehensive Health Assessment Program; CI = confidence interval; HOPES = Helping Older People Experience Success; NA = not applicable; NR = not reported; OR = odds ratio; RCT = randomized controlled trial; RR = relative risk; UK = United Kingdom; USPSTF = United States Preventive Services Task Force

<sup>a</sup> Sample size for cervical cancer screening only; several studies assessed multiple clinical preventive services. Mean age was reported for entire population (not limited to cervical cancer screening population).

<sup>b</sup> The CHAP group included people randomized to CHAP or CHAP + ASK; The No CHAP group included those randomized to ASK or usual care

<sup>c</sup> The ASK group included people randomized to ASK or CHAP + ASK; The No ASK group included those randomized to CHAP or usual care

<sup>d</sup> Includes 8 women who consented to screening but were unable to physically complete screening

#### 3.3.2.3 Colorectal Cancer Screening

One RCT<sup>107</sup> and two NRSIs<sup>115,116</sup> evaluated interventions to increase colorectal cancer screening in people with disabilities (Table 34).

##### 3.3.2.3.1 Cognitive/Intellectual/Developmental Disability

Two studies of interventions to increase colorectal cancer screening in people with cognitive/IDD provide limited evidence on effectiveness.<sup>115,116</sup> Both studies were specifically designed to increase colorectal cancer screening uptake. One uncontrolled cohort study identified 239 community-based people with cognitive/IDD who were eligible for colorectal cancer screening but had not undergone screening.<sup>115</sup> People with cognitive/IDD received specially written, “easy read” screening letters designed to encourage their participation in screening. Clinic staff also received special training to increase confidence and decrease potential embarrassment surrounding screening conversations. After 12 weeks, the study found 61 percent (117/239) of the eligible population had undergone screening, resulting in a screening rate that

### 3.3 Results, Key Question 2. Effectiveness of interventions

was similar to the national average at the time. The second study used a before-after design, and delivered a 2-hour, interactive education session to 137 people with cognitive/IDD on the importance of colorectal cancer screening.<sup>116</sup> The study found a substantial increase in the proportion of participants who said they intended to participate in screening immediately following the intervention versus before the intervention (99% vs. 39%; RR 2.55 (95% CI, 2.06 to 3.15), but actual rates of colorectal cancer screening uptake were not reported.

#### 3.3.2.3.2 Serious Mental Illness

The previously described RCT (Section 3.3.2.1.4) comparing the HOPES intervention with usual care assessed colorectal cancer screening rates in 177 people with serious mental illness.<sup>107</sup> The trial found similar rates of colorectal cancer screening in both the intervention and control groups at 3-year followup (82% [71/87] vs. 84% [76/90]; RR 0.97, 95% CI, 0.85 to 1.10).

**Table 34. Studies of interventions to improve the receipt of colorectal cancer screening**

Disability	Author, Year Study Design Duration of Followup	Sample Size Mean Age	Intervention Comparator	Results
Cognitive/intellectual/ developmental disability	Bowler 2015 <sup>115</sup> Prospective, uncontrolled cohort 12 weeks	N=239 Mean age NR Screening conducted according to National Bowel Screening Programme (UK)	Easy-read screening letter for people with cognitive/IDD and clinic staff training vs. NA	Colorectal cancer screening: 61% (117/239)
	Gray 2021 <sup>116</sup> Before-after Immediate post- intervention	N=137 Mean age NR; 86% <50 years, 14% >50 years Screening conducted according to Public Health Scotland (2020) guidelines	2-hour interactive education session, After vs. 2-hour interactive education session, Before	Intent to participate in colorectal cancer screening: 99% (135/137) vs. 39% (53/137); RR 2.55 (95% CI, 2.06 to 3.15)
Serious mental illness	Bartels, 2014 <sup>107</sup> RCT 3 years	N=177 Mean age: 60 years Screening conducted according to USPSTF (2013) recommendations	HOPES vs. Usual care	Colorectal cancer screening: 82% (71/87) vs. 84% (76/90); RR 0.97 (95% CI, 0.85 to 1.10)

Abbreviations: CI = confidence interval; HOPES = Helping Older People Experience Success; IDD = intellectual/developmental disability; NA = not applicable; NR = not reported; RCT = randomized controlled trial; RR = relative risk; UK = United Kingdom; USPSTF = United States Preventive Services Task Force

#### 3.3.2.4 Depression Screening in Adults

##### 3.3.2.4.1 Sensory Disability

One before-after study assessed the effect of an intervention designed to increase rates of depression screening in people with low vision, defined in this study as vision impairment that cannot be fully corrected with glasses, contact lenses or medical intervention and causes functional impairment.<sup>97</sup> The study followed the Welsh government recommendation that vision care providers should screen potential high-risk groups for depression. The study included 40 vision care providers who underwent a specialized training session that included an online lecture and a face-to-face workshop, aimed at educating practitioners about depression screening

### 3.3 Results, Key Question 2. Effectiveness of interventions

guidelines and practices. The screening intervention consisted of two questions asked of people with low vision about feelings of depression and hopelessness in the preceding month. Following the educational intervention, the proportion of practitioners who reported they conducted depression screening more than half of the time during vision care visits rose from 7.5 percent (3/40) at baseline to 62.5 percent (15/40).

#### 3.3.2.5 Hypertension Screening in Adults

Three RCTs<sup>107,111,112</sup> and one cross-sectional study,<sup>120</sup> assessed interventions that included reporting of blood pressure measurement in people with disabilities (Table 35).

##### 3.3.2.5.1 Cognitive/Intellectual/Developmental Disability

Two RCTs<sup>111,112</sup> and one cross-sectional study<sup>120</sup> included blood pressure measurement as part of an intervention designed to enhance general preventive care uptake in people with cognitive/IDD. As described in Section 3.3.2.1.2., one of the trials compared the CHAP with usual care (N=453)<sup>111</sup> and the other compared CHAP (n=123) with no CHAP (n=119), and the ASK health diary (n=121) with no ASK (n=121). In both trials, blood pressure screening rates ranged from 45 to 61 percent across intervention groups. Slightly higher rates of blood pressure screening were consistently found in the intervention groups relative to the control groups, though none of the between-group differences reached statistical significance (Table 35). The cross-sectional study reported overall higher rates of blood pressure screening, both in the comprehensive Health Check intervention group (91% [126/139]) and in the control group who did not have a comprehensive Health Check (64% [88/137]). After adjustment for the size of the primary care practice, people in the Health Check group were significantly more likely to have blood pressure screening (adjusted OR 5.5, 95% CI, 3.1 to 9.8).

##### 3.3.2.5.2 Serious Mental Illness

One RCT (n=177) of a year-long intervention that included weekly social skills training and monthly preventive care meetings for people with serious mental illness reported high uptake of blood pressure screening at 3-year followup.<sup>107</sup> In the study, nearly all the people included in both the intervention (100% [87/87]) and control (99% [89/90]) groups had undergone screening (RR 1.01, 95% CI, 0.98 to 1.04).

**Table 35. Studies of interventions to improve the receipt of hypertension screening**

Disability	Author, Year Study Design Duration of Followup	Sample size Mean age	Intervention Comparator	Results
Cognitive/intellectual/ developmental disability	Lennox, 2007 <sup>111</sup> Cluster RCT 1 year	N=453 Mean age: 39 years Screening conducted where “clinically indicated and according to national guidelines”	CHAP vs. Usual care	Blood pressure recorded: 50% (117/234) vs. 45% (99/219); RR 1.1 (95% CI, 0.8 to 1.5)
	Lennox, 2010 <sup>112</sup> Cluster RCT 1 year	N=242 Mean age: 36 years Screening conducted using general health promotion parameters	CHAP vs. No CHAP <sup>a</sup>	Blood pressure recorded: 59% (72/123) vs. 50% (60/119); adjusted OR 1.5 (95% CI, 0.8 to 2.9)

### 3.3 Results, Key Question 2. Effectiveness of interventions

Disability	Author, Year Study Design Duration of Followup	Sample size Mean age	Intervention Comparator	Results
	Lennox, 2010 <sup>112</sup> Cluster RCT 1 year	N=242 Mean age: 36 years Screening conducted using general health promotion parameters	ASK vs. No ASK <sup>b</sup>	Blood pressure recorded: 61% (71/121) vs. 48% (58/121); adjusted OR 1.6 (95% CI, 0.8 to 3.3)
	Durbin, 2019 <sup>120</sup> Cross-sectional NA	N=276 Mean age NR Screening conducted in all enrolled adults according to Canadian guidelines (2011)	Health Check vs. No Health Check	Blood pressure recorded: 91% (126/139) vs. 64% (88/137); adjusted OR 5.5 (95% CI, 3.1 to 9.8)
Serious mental illness	Bartels, 2014 <sup>107</sup> RCT 3 years	N=177 Mean age: 60 years Screening conducted according to USPSTF (2013) recommendations	HOPES vs. Usual care	Blood pressure screening: 100% (87/87) vs. 99% (89/90); RR 1.01 (95% CI, 0.98 to 1.04)

Abbreviations: ASK = Advocacy Skills Training; CHAP = Comprehensive Health Assessment Program; CI = confidence interval; HOPES = Helping Older People Experience Success; NA = not applicable; OR = odds ratio; RCT = randomized controlled trial; RR = relative risk; USPSTF = United States Preventive Services Task Force

<sup>a</sup> The CHAP group included people randomized to CHAP or CHAP + ASK; The No CHAP group included those randomized to ASK or usual care

<sup>b</sup> The ASK group included people randomized to ASK or CHAP + ASK; The No ASK group included those randomized to CHAP or usual care

#### 3.3.2.6 Prediabetes/Type 2 Diabetes Screening

##### 3.3.2.6.1 Cognitive/Intellectual/Developmental Disability

One cross-sectional study comparing a comprehensive Health Check with no Health Check reported on screening for type 2 diabetes using HbA1c testing in people with cognitive/IDD.<sup>120</sup> The study tested anyone with a BMI > 29 kg/m<sup>2</sup> or over age 39 years according to Canadian Diabetes Association guidelines, which differ from USPSTF guidelines<sup>48</sup> in testing everyone over age 39. Among 82 people meeting criteria for testing in this study, 80 percent (37/46) of the intervention group and 61 percent (22/36) of the control group received HbA1c testing (adjusted OR 2.5, 95% CI, 0.9 to 6.8), suggesting that the Health Check was associated with a large increase in testing likelihood compared with no Health Check.

#### 3.3.2.7 Falls Prevention

##### 3.3.2.7.1 Physical Disability

We did not identify any studies of fall prevention in people with disabilities ≥ 65 years at risk of falls, which is the age range supported by the USPSTF recommendation (Appendix A, Table A-2). However, one potentially informative RCT compared use of a falls prevention intervention with no intervention in people with physical disability with a mean age of 56 years.<sup>110</sup> The study randomized 30 people with multiple sclerosis and a 2-month history of ≥ 2 falls to Free From Falls Online (n=15) or control (n=15). The study participants were 70 percent female and 97 percent White race. The intervention was an 8-week web-based adaptation of an in-person program (Free From Falls) that included weekly webinars on fall prevention strategies,

### 3.3 Results, Key Question 2. Effectiveness of interventions

downloadable materials that could be printed or viewed online, and an exercise video. The web-based content was specifically designed to minimize barriers for people with multiple sclerosis. Although study participants generally expressed satisfaction with the intervention, at 5-month followup there was no clear difference between groups in incidence of falls (93% [13/14] vs. 100% [15/15]; RR 0.93, 95% CI, 0.77 to 1.12).

#### 3.3.2.8 Weight Loss to Prevent Obesity-Related Morbidity and Mortality

##### 3.3.2.8.1 Cognitive/Intellectual/Developmental Disability

One RCT<sup>111</sup> and one uncontrolled cohort study<sup>118</sup> reported on interventions to promote weight loss to prevent obesity-related morbidity and mortality in people with cognitive/IDD (Table 36). The trial<sup>111</sup> comparing CHAP with usual care (described in Section 3.3.2.1.2) reported on the number of obese people who received a weight management plan from their physician, finding that people in the CHAP group were more likely to have a weight management plan (41% [7/17]) than those in the usual care group (25% [1/4]). This finding is limited by the small numbers of patients in each group, and the resulting risk estimate was not statistically significant (RR 1.65, 95% CI, 0.28 to 9.86).

The cohort study<sup>118</sup> was designed to assess a health promotion program (Steps to Your Health) that was adapted for people with cognitive disability. The study included 192 people (mean age 39 years; 67% female) with a BMI  $\geq 25$  kg/m<sup>2</sup> and cognitive disability ranging from mild to severe. Fifty-two percent of the population was White race, and 48 percent were Black. From baseline to 9-week followup, the study found a mean change in BMI of -0.31 kg/m<sup>2</sup> ( $p \leq 0.001$ ) and an increase in exercise frequency of 1.39 times per week ( $p \leq 0.001$ ). Subgroup analysis found BMI mean change was higher in women versus men (-0.39 versus -0.16), Black participants versus White participants (-0.44 vs. -0.19), but tests for interaction were not reported. When stratified according to cognitive disability type, people with Down Syndrome (7% of the study population) had a mean gain in BMI (0.18 kg/m<sup>2</sup>) while those without Down Syndrome had a BMI loss of -0.35 kg/m<sup>2</sup>. Regression analysis of predictors of a loss of BMI 0.81 kg/m<sup>2</sup> (about 2.3 kg) found a significant effect for women (adjusted OR 2.32, 95% CI, 1.03 to 5.21) but not for other factors including Black race (adjusted OR 1.28, 95% CI, 0.63 to 2.62), age (adjusted OR 1.01, 95% CI, 0.97 to 1.04), IQ (adjusted OR 1.00, 95% CI, 0.97 to 1.03), or change in exercise frequency (adjusted OR 1.04, 95% CI, 0.96 to 1.13).

**Table 36. Studies of interventions to promote weight loss to prevent obesity-related morbidity and mortality**

Disability	Author, Year Study Design Duration of Followup	Sample size Mean age	Intervention Comparator	Results
Cognitive/intellectual/ developmental disability	Lennox, 2007 <sup>111</sup> Cluster RCT 1 year	N=21 Mean age: 39 years Screening conducted where "clinically indicated and according to national guidelines"	CHAP vs. Usual care	Weight management plan: 41% (7/17) vs. 25% (1/4); RR 1.65 (95% CI, 0.28 to 9.86)

### 3.3 Results, Key Question 2. Effectiveness of interventions

<b>Disability</b>	<b>Author, Year Study Design Duration of Followup</b>	<b>Sample size Mean age</b>	<b>Intervention Comparator</b>	<b>Results</b>
	Mann 2006 <sup>118</sup> Uncontrolled cohort 9 weeks	N=192 Mean age: 39 years Intervention delivered to those with a BMI $\geq$ 25 kg/m <sup>2</sup> at baseline	Modified Steps to Your Health, baseline vs. Modified Steps to Your Health, followup	BMI, baseline vs. followup: 35.38 (SD 6.85) vs. 35.07 (SD 6.59); mean change - 0.31 (p $\leq$ 0.001)  Exercise frequency (times/week), baseline vs. followup: 3.24 (SD 3.93) vs. 4.62 (SD 1.39); mean change 1.39 (p $\leq$ 0.001)

Abbreviations: BMI = body mass index; CHAP = Comprehensive Health Assessment Program; CI = confidence interval; RCT = randomized controlled trial; RR = relative risk; SD = standard deviation

<sup>a</sup> The CHAP group included people randomized to CHAP or CHAP + ASK; The No CHAP group included those randomized to ASK or usual care

<sup>b</sup> The ASK group included people randomized to ASK or CHAP + ASK; The No ASK group included those randomized to CHAP or usual care



### **3.4 Results, Key Question 3. Characteristics of interventions that mitigate barriers to clinical preventive services**

#### **3.4 Key Question 3. What are the characteristics and/or components of interventions that contribute to their effectiveness (or lack of effectiveness) in mitigating barriers to the receipt of clinical preventive services among people with disabilities?**

Evidence on how intervention characteristics contribute to effectiveness was available from two studies<sup>117,118</sup> and was very limited. The previously described uncontrolled study of an intervention to promote weight loss in people with BMI  $\geq 25\text{kg/m}^2$  and cognitive disability found people who attended all eight of the intervention sessions had a greater change in BMI compared with those who attended  $\leq 7$  sessions (-0.55 vs. -0.11  $\text{kg/m}^2$ ;  $p=\text{NR}$ ).<sup>118</sup> A case-control study<sup>117</sup> that reported on screening uptake when D/deaf people had access to an ASL interpreter during clinic visits found that satisfaction with patient-provider communication was associated with increased breast cancer ( $p=0.01$ ) and cervical cancer ( $p=0.04$ ) screening.

### **3.5 Results, Key Question 4. Harms of interventions that mitigate barriers to clinical preventive services**

#### **3.5 Key Question 4. What are the harms of intervention programs to mitigate barriers to the receipt of clinical preventive services among people with disabilities?**

Harms of interventions were generally not reported. One RCT<sup>112</sup> narratively reported no adverse effects associated with the CHAP. The same study reported that participants randomized to ASK were significantly less likely to have a physician-assigned weight management plan compared to those randomized to no ASK (10% [12/121] vs. 27% [22/121]; OR 0.4, 95% CI, 0.2 to 0.7). Study investigators deemed this a chance finding and not directly related to the intervention. No other studies reported harms.

# Chapter 4. Discussion

## 4.1 Key Findings

People with disabilities are a substantial portion of the population. Although it has long been recognized that people with disabilities have at least the same need for health maintenance and preventive services as the general population, long-standing disparities in the receipt of various clinical preventive services persist among people with disabilities. The purpose of this systematic review was: to document and summarize identified barriers and facilitators to the receipt of selected clinical preventive services among people with disabilities (Key Question 1); and to identify and synthesize the literature on the effectiveness of interventions to improve the receipt of selected clinical preventive services among people with disabilities (Key Questions 2-4).

Studies have found disparities in the receipt of preventive services to vary according to type of disability,<sup>21,37,38</sup> which suggests that the receipt of different clinical preventive services by people with different types of disability may be influenced by different barriers/facilitators and/or influenced differentially by particular barriers/facilitators. This view reflects the diverse nature of different types of disability (e.g., mobility, sensory, cognitive/ intellectual /developmental; serious mental illness), with each presenting different types of potential challenges for the receipt of preventive services; and the variety of different preventive services, each with different functional requirements and potential barriers for participation. It also reflects the complex interactions of individuals' functional abilities with various environmental factors (physical, social, attitudinal), consistent with the integrative model of human functioning and disability represented by the ICF of the WHO.<sup>39</sup> In consideration of these factors, we organized and presented the findings of this systematic review for individual clinical preventive services, according to individual types of disability.

Sixty-eight studies provided evidence for this systematic review – 54 studies were included for Key Question 1 and 16 studies were included for Key Question 2. Two of the included studies had limited evidence for Key Question 3 (regarding the effectiveness of particular characteristics or components of interventions in mitigating barriers to the receipt of clinical preventive services), and one included study had limited evidence on the harms of intervention programs (Key Question 4).

**Key Question 1.** For Key Question 1, studies related to 10 of the 20 clinical preventive services included in the review: screening for anxiety disorder in adults (n=1); breast cancer screening (n=36); cervical cancer screening (n=19); colorectal cancer screening (n=6); screening for depression risk in adults (n=3); screening for HIV infection (n=1); screening for unhealthy alcohol use (n=2); interventions for falls prevention in community-dwelling older adults (n=1); counselling for healthy diet and physical activity for CVD prevention (n=1); and behavioral counselling to prevent sexually transmitted infections (n=3). By far, the largest number of studies were related to barriers/facilitators for the receipt of breast cancer screening (69%) and/or cervical cancer screening (35%), and addressed barriers/facilitators for people with cognitive/ intellectual/ developmental disabilities (47%) or physical disabilities (36%). Table G-1 in Appendix G presents the included studies according to the clinical preventive service(s) and type(s) of disability addressed.

For **breast cancer screening**, most categories of barriers/facilitators (environment-level, person-level, provider-level, healthcare system-level, accessibility of healthcare facility, accessible communication) were reported for all types of disability. Among women with

## Chapter 4. Discussion

**physical disabilities**, most reported barriers were at the person level (e.g., difficulty standing still, fear and/or embarrassment), the provider level (e.g., ableism, lack of knowledge about people with disabilities) and the level of the healthcare system (e.g., difficulty booking/attending appointments). Most reported facilitators were at the provider level (e.g., knowledge about people with disabilities). Among women with **cognitive, intellectual, and/or developmental disabilities**, most reported barriers were at the environment level (e.g., family/caregiver feeling overwhelmed, transportation), the person level (e.g., fear and/or embarrassment, inability to give informed consent), and the provider level (e.g., lack of knowledge about people with disabilities, not assessing the need for a decision-making delegate). Most reported facilitators were at the person level (e.g., feeling in control, having coping strategies), the provider level (e.g., allowing preparatory visits, providing explanations before the procedure) and the level of the healthcare system (e.g., extra time for appointments).

For **cervical cancer screening** among women with **physical disabilities**, most reported barriers were at the person level (e.g., feeling dependent on others, pain or discomfort with screening) and the provider level (e.g., negative attitude/ableism, not listening to the person with disabilities). Most reported facilitators were at the provider level (e.g., assistance with dressing, knowledge about people with disabilities). Among women with **cognitive, intellectual, and/or developmental disabilities**, most reported barriers were at the person level (e.g., inability to give informed consent, not understanding the screening process) and the provider level (e.g., ableism, misconceptions about sexual activity and need for screening). Most reported facilitators were at the provider level (e.g., adjusting procedures to accommodate the patient, providing an explanation before the procedure).

Studies on **colorectal cancer screening** pertained to people with **physical disabilities** (n=4) or people with **serious mental illness** (n=2). Most categories of barriers/facilitators (environment-level, person-level, provider-level, healthcare system-level, accessibility of healthcare facility) were reported for both types of disability.

For each of the other preventive services, there were fewer studies and barriers/facilitators were reported for one or two types of disability: **screening for depression risk** in adults (3 studies; cognitive/intellectual/developmental disability, sensory disability); behavioral **counselling to prevent sexually transmitted infections** (3 studies; physical disability; serious mental illness); screening for unhealthy alcohol use (2 studies; cognitive/ intellectual/ developmental disability); **screening for HIV infection** (1 study; sensory disability); **interventions for falls prevention** in community-dwelling older adults (1 study; cognitive disability); and **counselling for healthy diet and physical activity for CVD prevention** (1 study; serious mental illness).

**Key Question 2.** For Key Question 2, studies related to 8 of the 20 clinical preventive services included in the review: breast cancer screening (n=8), cervical cancer screening (n=9), colorectal cancer screening (n=3), screening for depression risk in adults (n=1), screening for hypertension (n=4), screening for prediabetes/type 2 diabetes (n=1), interventions for falls prevention in community-dwelling older adults (n=1), and interventions for weight-loss to prevent obesity (n=3); seven of the studies assessed multiple clinical preventive services. Ten studies were of interventions directed at people with disabilities, two studies were of interventions for clinicians, and four studies were of multicomponent interventions targeting both people with disabilities and clinicians. Studies included people with physical disabilities (n=3), cognitive/intellectual/developmental disabilities (n=8), sensory disabilities (n=4), and serious

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mental illness (n=1). The largest number of studies were of interventions to improve the receipt of breast cancer screening (50%) and/or cervical cancer screening (56%), and pertained to people with cognitive/intellectual/developmental disabilities (50%), sensory disabilities (25%), or physical disabilities (19%).

Eight studies (five randomized controlled trials [RCTs]) assessed interventions to improve the receipt of **breast cancer screening** among women with different types of disability. In general, the RCTs found that educational and health advocacy interventions were associated with increased receipt of breast cancer screening, although risk estimates were not consistently statistically significant. One cluster RCT among women with **cognitive/intellectual/developmental disabilities** found that, compared with usual care, women who participated in an intervention that targeted general health promotion – Comprehensive Health Assessment Program (CHAP) – were more likely to receive a mammogram within 1 year (RR 3.5, 95% CI, 1.1 to 12), although the proportion receiving a mammogram was low for both groups (15% vs. 4%).<sup>111</sup> Another RCT among people with **serious mental illness** found that, compared with usual care, women who participated in a 1-year, multicomponent intervention that targeted general health care – Helping Older People Experience Success (HOPES) – were more likely to receive a mammogram within 3 years (RR 1.27, 95% CI, 1.02 to 1.59; 85% vs. 67%).<sup>107</sup> One RCT of an educational intervention designed to improve breast and cervical cancer screening among women with **physical disabilities** did not find a significant difference in the receipt of mammography after 6 months (RR 1.16, 95% CI, 0.79 to 1.70; 49% vs. 42%);<sup>113</sup> and one RCT of an educational intervention designed to improve breast cancer screening among women with a **sensory disability** (deafness) did not find a significant difference in the receipt of mammography after 1 year (RR 1.05, 95% CI, 0.84 to 1.32; 66% vs. 63%).<sup>108</sup>

Nine studies (four RCTs) assessed interventions to improve the receipt of **cervical cancer screening** among women with different types of disability. In general, the RCTs found that educational and health advocacy interventions were associated with increased receipt of cervical cancer screening. One RCT among women with **physical disabilities** found that, compared with receiving general health promotion materials, women who participated in an intervention designed to improve breast and cervical cancer screening – Promoting Access to Health Services (PATHS) – were more likely to receive a Pap test within 6 months (RR 2.20, 95% CI, 1.15 to 4.19; 61% vs. 27%).<sup>113</sup> One cluster RCT among women with **cognitive/intellectual/developmental disabilities** found that, compared with usual care, women who participated in an intervention that targeted general health promotion – CHAP – were more likely to receive a Pap test within 1 year (RR 7.9, 95% CI, 1.8 to 35), although the proportion receiving a Pap test was low for both groups (16% vs. 2%).<sup>111</sup> Another RCT among people with **serious mental illness** found that, compared with usual care, women who participated in a 1-year, multicomponent intervention that targeted general health care – HOPES – were more likely to receive a Pap test within 3 years (RR 1.58, 95% CI, 1.15 to 2.16; 77% vs. 49%).<sup>107</sup> One RCT of an intervention specifically designed to increase cervical cancer screening rates in women with a **sensory disability** (deafness) found a large but imprecise effect on screening rates (RR 23, 95% CI, 3.18 to 166).

Three studies (one RCT) assessed interventions to improve the receipt of **colorectal cancer screening** among people with cognitive/intellectual/developmental disabilities or serious mental illness. The RCT was the only comparative study that reported on the receipt of colorectal cancer screening as an outcome, and was also included for breast cancer and cervical cancer screening, described above. The study was of a 1-year, multicomponent intervention that targeted general

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health care among people with **serious mental illness** – HOPES – and found similar rates of colorectal cancer screening in both the intervention and control groups at 3-year followup (RR 0.97, 95% CI, 0.85 to 1.10; 82% vs. 84%).<sup>107</sup>

Four studies (three RCTs) reported on the receipt of **screening for hypertension** as an outcome in interventions to improve general health care among people with **cognitive/intellectual/ developmental disabilities** or **serious mental illness**. None of the studies found a difference in rates of hypertension screening between the intervention and usual care.

Two studies (one RCT) reported on interventions to improve general health that reported on outcomes related to **weight loss to reduce obesity-related morbidity**, among people with **cognitive/intellectual/developmental disabilities**. The RCT found that people with obesity who received the intervention were more likely to have a weight management plan than those in the usual care group (RR 1.65, 95% CI, 0.28 to 9.86; 41% [7/17] vs. 25% [1/4]), but the findings were limited by the small numbers of patients in each group, and the resulting risk estimate was not statistically significant.<sup>111</sup> A single-arm study assessed a health promotion program (Steps to Your Health) that was adapted for people with **cognitive disability**. The intervention was associated with significant changes in BMI and exercise frequency between baseline and followup at 9 weeks.<sup>118</sup>

Evidence on interventions to improve the receipt of other clinical preventive services (**screening for depression risk in adults, screening for prediabetes/type 2 diabetes, and interventions for falls prevention**) is limited to one study for each preventive service, with no clear effect of the interventions for any preventive service.

### 4.2 Strengths and Limitations of the Systematic Review Process

**Strengths.** Our systematic review has some notable strengths. The scope and focus of the review were developed and refined with input from Key Informants and Technical Expert Panel members that included the perspectives of end-users and people with disabilities. The protocol was reviewed by Technical Expert Panel members.

It has been previously recognized that the diversity of definitions of disability – which may be based on health conditions and/or aspects of functional ability – presents a challenge for conducting a literature search on this topic.<sup>47</sup> To address that challenge, our database search strategy was informed by an earlier search strategy,<sup>47</sup> which used the ICF concept of disability, and was refined with additional MeSH terms and keywords to meet the needs of this review.

The review was limited to a set of clinical preventive services, each of which has an evidenced-based recommendation from the USPSTF, representing various general types of preventive services and a breadth of health conditions and circumstances. The included preventive services are also characterized by a variety of different functional requirements and potential barriers for participation, with relevance to people with different types of disability.

As noted previously, the receipt of different clinical preventive services by people with different types of disability may be influenced by different barriers/facilitators and/or influenced differentially by particular barriers/facilitators, consistent with the ICF model.<sup>39</sup> Taking this potential interactive effect into account, we organized and presented the findings of this review for individual clinical preventive services, according to individual types of disability.

**Limitations.** In addition to the limitations of the evidence base described below, there are limitations to the review that are the result of processes and decisions we made in applying standard methods for systematic reviews and adapting these methods to this specific topic and

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Key Questions. The scope of this review focused on barriers/facilitators related specifically to the receipt of clinical preventive services. However, we considered for inclusion studies of interventions that addressed factors other than preventive services (e.g., general access to healthcare), provided that the study assessed and reported the effect of the intervention on included outcomes related to included preventive services. Because our literature search was designed to focus on the receipt of preventive services, as per the scope of the review, it is possible that our search did not identify some relevant studies of interventions that were not targeted specifically at preventive services.

Although we worked with the Technical Expert Panel to develop a diverse set of clinical preventive services to include for the review, we did not include all possible preventive services with evidence-based recommendations, and it is possible that potentially informative studies have been conducted related to preventive services outside the scope of this review.

For Key Question 1, when classifying barriers and facilitators as reported by individual studies into the broad general categories used for this review, our team members consulted with one another for consistency within and across preventive services. We followed a similar process when deciding on summary terms for common barriers and facilitators reported by individual studies. Nevertheless, summarizing and synthesizing in this way requires subjective judgements, some barriers/facilitators might reasonably be considered to fall within different categories, and it is possible that others might make different judgements.

Although we did include studies of *individuals* with multiple, co-occurring types of disability, we did not otherwise include studies of various different types of disability, unless the study reported barriers/facilitators as related to the specific type of disability and/or made clear that reported barriers/facilitators applied to all of the included types of disability. It is possible that our review thereby missed studies that provide different information about unique barriers and/or facilitators that apply across disability types.

One limitation of our systematic review process is a result of the limitations of the evidence base. Due to the high methodological and clinical heterogeneity of the included studies (populations, interventions, outcomes, and study designs), we did not attempt to assign strength of evidence ratings for Key Question 2. To do so would raise concern that indirect comparisons between various heterogeneous interventions would not meaningfully address the questions and would lead to unreliable and potentially misleading conclusions. For the same reason – particularly the high methodological and clinical heterogeneity of the intervention strategies – we did not conduct quantitative pooled syntheses (meta-analyses). This heterogeneity is also challenging for qualitative synthesis of the studies.

### 4.3 Limitations of the Evidence Base

The most notable limitation of the body of evidence for this review is the lack of relevant studies for most of the clinical preventive services – both for the descriptive question documenting reported barriers and facilitators (Key Question 1), and the questions related to the effectiveness of interventions (Key Questions 2-4). By far, most of the evidence was for two preventive services – breast cancer screening and cervical cancer screening – a finding that is consistent with previous studies on disparities in the receipt of preventive services among people with disabilities, the preponderance of which are also on breast and cervical cancer screening (and, to a lesser extent, colorectal cancer screening).

Although we identified 54 studies for Key Question 1, these studies related to only 10 of the 20 preventive services included for the review; and the evidence for 7 of those 10 preventive

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services was based on three or fewer studies each, with only one study included for each of four preventive services. Only 16 studies were identified for Key Question 2, related to only 8 of the 20 preventive services included for the review; and the evidence for five of those 8 preventive services was based on three or fewer studies each, with only one study included for each of three preventive services. Furthermore, for most of the preventive services for which evidence was found, the studies pertained to only one or two types of disability. For Key Question 1 and Key Question 2, the evidence for 50 percent of the preventive services (5/10 and 4/8, respectively) pertained to only one type of disability; with 80 percent of the preventive services in Key Question 1 (8/10) and 75 percent of those in Key Question 2 (6/8) having evidence pertaining to two or fewer types of disability. Aside from the absence of any evidence for most preventive service-disability type combinations, these limitations in the body of evidence also substantially limit any comparisons between preventive services and/or types of disability. Even for the two preventive services with the most evidence – breast cancer screening and cervical cancer screening – only one or two studies pertained to any specific disability type, except for cognitive/intellectual/developmental disabilities.

The evidence base for Key Question 2 is further limited by the designs and quality of the included studies. Seven RCTs were identified for Key Question 2, but most of the studies were not randomized trials, including: before-after studies, nonrandomized trials, two cross-sectional studies, and single-arm, noncomparative studies, which were included based on the best evidence approach, given the relative lack of evidence (particularly RCTs) for many preventive service-disability types. In addition, few studies were rated as low risk of bias, with most rated as moderate risk of bias. Common methodological limitations of the RCTs included unclear randomization and allocation concealment, and unclear or lack of blinding of outcome assessors. Common methodological limitations of the observational studies and nonrandomized intervention studies included missing details about baseline characteristics of study participants, loss to followup, and maintenance of comparable intervention groups.

As noted in above, another limitation of the evidence base was the high methodological and clinical heterogeneity of the included studies, due to which we did not attempt to assign strength of evidence ratings for Key Question 2, nor to conduct quantitative pooled syntheses (meta-analyses).

### 4.4 Applicability

A number of factors could affect the applicability of the findings of the review. The scope of the review included people with four general types of disabilities, a set of 20 clinical preventive services with Grade A or Grade B recommendations from the USPSTF (as of September 27, 2023), and specific outcomes related to the receipt of those preventive services. For each preventive service, we limited the included studies to those in which the study population and the intervention were consistent with the population(s) and intervention(s) that were explicitly recommended by the USPSTF. For example, the USPSTF recommendation for breast cancer screening applied only to the use of screening mammography; and the USPSTF recommendation on interventions for falls prevention in community-dwelling older adults only applied to exercise-based interventions. In addition, although the review included a range of types of disability (physical; cognitive/ intellectual/ developmental; sensory; serious psychiatric/mental illness), the evidence for specific types of disability for most included preventive services is limited or lacking entirely. Therefore, if judging the applicability of the findings of the review for particular populations, it would be important to consider the specific type(s) of disability for



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which evidence was identified for a given preventive service, as well as the specific population(s) and intervention(s) that were included in the USPSTF recommendation for that preventive service. For example, the evidence on barriers/facilitators for behavioral counselling to prevent sexually transmitted infections (Key Question 1) only applies to people with serious mental illness; and the evidence on interventions to improve the receipt of colorectal cancer screening (Key Question 2) applies only to people with cognitive/intellectual/developmental disabilities or people with serious mental illness, with different interventions studied for each of these types of disability.

Included studies were conducted in a range of populations and settings (Key Question 1 and 2), and represented a range of interventions (Key Question 2), many of which were designed and/or tailored specifically for a given population and/or setting. Therefore, if judging the applicability of particular barriers/facilitators (Key Question 1) for a given preventive service, it would be important to consider the specific setting(s) in which those barriers/facilitators were identified (e.g., country, type of healthcare system, type of physical facility). Similarly, if judging the applicability of the review findings related to a particular intervention to improve the receipt of a given preventive service (Key Question 2), it would be important to consider the specific setting in which any supporting studies were conducted and ways in which the intervention may have been limited to that setting.

### 4.5 Implications for Clinical and Policy Decisions

The long-standing, persistent disparities in the receipt of various clinical preventive services among people with disabilities requires improvements that will involve clinical and policy decisions. While the findings of this review do not provide clear or sufficient evidence to support any specific clinical or policy decisions, they may have some general implications. Although the reported barriers and facilitators (Key Question 1) were mostly limited to a small number of preventive services (particularly breast cancer screening and cervical cancer screening), the broad range of barriers reported across general categories (e.g., environment-level, person-level, provider-level, healthcare system-level) suggests the potential benefit of clinical and policy decision makers using a broad conception of “accessibility” – that is, a conception that includes barriers and facilitators of various different types and also considers the potential combined and/or interactive effects of those diverse barriers/facilitators. As an example, for breast cancer screening among women with physical disabilities, numerous studies reported barriers and facilitators within multiple categories; environment-level, person-level, provider-level, healthcare system-level, and related to the accessibility of facilities. In making clinical or policy decisions about improving the receipt of breast cancer screening, all of these categories should be considered. For a woman who uses a wheelchair, it may not be enough for a facility to install an adjustable mammography machine if her physician does not believe that she has the same need for screening as someone without a physical disability, if accessible transportation is not available, and/or if her clinic does not provide extra time for appointments.

The findings of this review do not provide clear or sufficient evidence to support any specific clinical or policy decisions regarding the effectiveness of interventions to improve the receipt of clinical preventive services for people with disabilities (Key Question 2). However, three RCTs that assessed breast cancer screening and cervical cancer screening found that various educational and health advocacy interventions were associated with increased rates of screening among women with physical disabilities, cognitive/intellectual/developmental disabilities, and serious mental illness. The evidence came from three RCTs of three different interventions –

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each of which targeted a different type of disability and assessed both breast and cervical cancer screening – “PATHS” for women with physical disabilities,<sup>113</sup> “CHAP” for people with cognitive/ intellectual/ developmental disabilities,<sup>111</sup> and “HOPES” for people with serious mental illness.<sup>107</sup> The “PATHS” intervention was specific to breast and cervical cancer screening, while “CHAP” and “HOPES” targeted general preventive care. Although each of these interventions was found to improve the receipt of breast and cervical cancer screening (findings were statistically significant, except for breast cancer screening among women with physical disabilities), the evidence is limited to a single RCT for each preventive service-disability type. While the evidence does not provide clear support for any specific clinical or policy decisions, these interventions might be adopted or adapted and/or serve as models for the development, implementation, and evaluation of similar approaches in other populations and settings.

### 4.6 Future Research Needs

The findings of this systematic review underscore the lack of evidence specific to: (1) barriers and facilitators to the receipt of clinical preventive services for people with disabilities, and (2) interventions to improve the receipt of preventive services for people with disabilities. As described above, the most notable limitation of the body of evidence is the lack of studies for most of the clinical preventive services – both for documenting reported barriers and facilitators (Key Question 1), and related to the effectiveness of interventions (Key Questions 2-4). Furthermore, for most of the preventive services for which evidence was found, the studies pertained to few types of disability. Even for breast cancer and cervical cancer screening – the two preventive services with the strongest prior evidence base establishing the existence of disparities and the most studies in the current review reporting multiple barriers and facilitators – the evidence on interventions to improve receipt of the services (Key Question 2) is limited to few studies of rigorous design and low risk of bias.

Clearly, there is a need for research to address the substantial gaps in the evidence for this important topic – research into the barriers and facilitators for receipt of preventive services that have not been well-studied previously, and research into interventions to mitigate the barriers. While we did not limit the included preventive services for the review to those for which the existence of disparities among people with disabilities was previously well-established, we found little or no evidence for some preventive services for which disparities among people with disabilities have been reported, albeit not in many studies.<sup>20,26,27,125</sup> Because research priorities might be guided by the existence of clear disparities in care, future research should include studies of possible disparities in the receipt of preventive services that have not been well-studied previously. For practical reasons related to definitions/measures of disability and clinical data that are or are not routinely gathered, studying certain preventive services may be more challenging than studying others; however, establishing the existence and magnitude of disparities in the receipt of specific preventive services among people with various types of disability could help to prioritize and guide research into the associated barriers/facilitators and, subsequently, into the development and evaluation of targeted interventions to mitigate the barriers. Research into barriers and facilitators to the receipt of preventive services should include the perspectives and experience of people with disabilities, as well as that of individuals

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representing all other relevant roles (e.g., caregivers, clinicians or other healthcare workers, administrators).

As with clinical and policy decision making, future research into the development, implementation, and evaluation of interventions to improve the receipt of preventive services among people with disabilities should reflect an understanding of the various different categories and types of barriers and facilitators for a given preventive service-disability type, as well as the potential combined and/or interactive effects of those diverse barriers/facilitators. Such research might include randomized trials and nonrandomized implementation studies that address multiple categories of barriers, to investigate possible “synergy” between the elements of the intervention. For example, a trial might investigate the effectiveness of two interventions, separately and in combination – an educational intervention for patients to increase knowledge and self-efficacy for breast-cancer screening and a complementary intervention for clinicians to increase knowledge and awareness of barriers to breast cancer screening faced by women with disabilities. Future research should also investigate the potential benefits of interventions designed to improve general healthcare for people with disabilities (e.g., clinic systems designed to learn and record patients’ particular needs for accessibility, improved general knowledge and awareness of disability among clinic staff, accessible communication) and how those interventions affect the receipt of various preventive services.

### 4.7 Summary and Conclusion

This systematic review included 54 studies that reported on barriers and facilitators to the receipt of clinical preventive services for people with disabilities (Key Question 1) and 16 studies that reported on interventions to improve the receipt of preventive services for people with disabilities (Key Question 2). Two included studies had limited evidence on the effectiveness of particular components of interventions (Key Question 3) and one study had limited evidence on harms of an intervention (Key Question 4). The findings were based on a broad literature search that included terms for conditions and functional elements of disability; and were organized according to individual clinical preventive service and general type of disability.

For both Key Question 1 and Key Question 2, evidence was lacking for most preventive services and generally limited to one or two types of disability for a given preventive service. Most evidence was for two preventive services – breast cancer screening and cervical cancer screening – consistent with previous studies on disparities in the receipt of preventive services among people with disabilities, the preponderance of which are also on breast and cervical cancer screening. For breast and cervical cancer screening, evidence on barriers/facilitators was included for all types of disability and most categories of barriers and/or facilitators were reported (Key Question 1). Three RCTs that assessed breast and cervical cancer screening found that various educational and health advocacy interventions were associated with increased rates of screening among women with physical disabilities, cognitive/intellectual/developmental disabilities, and serious mental illness (Key Question 2). The findings of this systematic review underscore the lack of evidence specific to these important Key Questions and the need for research to address the substantial gaps in the evidence for this important topic.

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## Abbreviations and Acronyms

<b>Abbreviation</b>	<b>Term</b>
ADA	Americans with Disabilities Act
ADL	activities of daily living
AHRQ	Agency for Healthcare Research and Quality
ASK	Advocacy Skills Training
ASL	American Sign Language
BMI	body mass index
BRFSS	Behavioral Risk Factor Surveillance System
CHAP	Comprehensive Health Assessment Program
CI	confidence interval
CVD	cardiovascular disease
EPC	Evidence-based Practice Center
HbA1C	Hemoglobin A1C
HOPES	Helping Older People Experience Success
IADL	instrumental activities of daily living
ICF	International Classification of Functioning, Disability, and Health
IDD	Intellectual/developmental disability
KQ	Key Question
LGBTQ+	Lesbian Gay Bisexual Transgender Queer/questioning plus/others
MMAT	Mixed Methods Appraisal Tool
NHIS	National Health Interview Survey
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
NRSI	nonrandomized studies of interventions
OR	odds ratio
PATHS	Promoting Access to Health Services
PICOTS	population, interventions, comparators, outcomes, timing, setting
PwD	people with a disability/person with a disability
RCT	randomized controlled trial
RR	relative risk
USPSTF	United States Preventive Services Task Force
WHO	World Health Organization