

Principles for Service Delivery: Best Practices for Cervical Screening for Women with Disabilities

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Background: Cervical cancer screening is an important public health priority, yet many marginalized groups are not reached by existing programs. The nearly 700 million women with disabilities globally face substantial barriers in accessing cervical cancer screening and have lower coverage, yet there is limited evidence on what would support enhanced uptake among this population.

Methods: We updated a systematic review to estimate the disparity in screening uptake for women with disabilities. We conducted a scoping review to understand key barriers and the inclusion of disability in existing screening policies and possible solutions to improve screening uptakes amongst women with disabilities. We then formulated key principles for improved service delivery for this group, targeted predominantly at clinicians.

Results: Our updated review identified an additional five new studies, and confirmed that women with disabilities were less likely to be screened for cervical cancer (RR=0.65, 0.50–0.84). Disability-specific barriers to accessing screening pertained to: (1) knowledge and autonomy; (2) logistics; and (3) stigma and fear. Few guidelines included specific considerations for women with disabilities. Our scoping review showed that improving access to care must focus on improving (1) autonomy, awareness, and affordability; (2) human resources; and (3) health facility accessibility.

Conclusion: Screening programmes and health providers must ensure women with disabilities are included in cervical cancer screening programmes and thereby help to achieve their right to health and eliminate cervical cancer as a public health issue.

Keywords: cervical cancer, screening, disability

Introduction

Cervical cancer remains the fourth leading cause of cancer among women worldwide, even though it is largely preventable and curable.¹ Consequently, the WHO launched the “Global Strategy for Cervical Cancer Elimination as a Public Health Problem” in 2020.² This strategy requires all countries to meet the 90–70–90 targets by 2030, meaning that 90% of girls are fully vaccinated with HPV vaccine by age 15, 70% of women have been screened for cervical cancer by 35, and again by 45, and 90% of women with identified with cervical disease receive treatment.² Elimination therefore depends on achieving high coverage of cervical screening for all women. However, currently, screening is recommended in only 139 (69%) of 202 countries and territories globally,³ and screening program guidelines vary widely.^{4,5} Moreover, adequate screening coverage is rare outside of high income settings.² Even within high income populations, certain groups of women are consistently less likely to undergo screening, such as ethnic minorities, sexual and gender minorities, or rural residents.⁶ One important group is women with disabilities, who make up a sizeable proportion of the target screening population (eg 18.7% of females in England),⁷ and are repeatedly found to be less likely to undergo cervical cancer screening.^{8,9}

Globally, 1.3 billion people have disabilities, including 700 million women.¹⁰ People with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.¹¹ Across the world, people

with disabilities are more likely to be poor and frequently face stigma and discrimination, resulting in poorer inclusion in education, employment, health and other aspects of society.¹² Women with disabilities face dual issues as they experience discrimination due to both their gender and disability status. On average they have worse health outcomes, including from cervical cancer, for a wide range of reasons.^{10,13,14} These include increased risk due to higher exposure to adverse social and economic determinants, behavioural risk factors such as smoking, higher levels of comorbidity, poorer access to diagnostic and potentially curative treatment in health and care services, as well as lower levels of screening.

The inequality in access to cervical cancer screening by women with disabilities is an important concern. Most critically, women with disabilities are more likely to die from cervical cancer compared to other women, as indicated by data from South Korea (HR women with disabilities versus without: 1.36, 95%CI: 1.25–1.48)¹⁵ and Sweden (HR women with mental health disorder versus without: 1.23, 95%CI: 1.07–1.42),¹⁶ although data is lacking for low and middle-income countries (LMICs). Moreover, disability is common and so missing this large segment of the population could derail the ability to reach screening and consequently elimination targets.² Access to health care is also a fundamental right for women with disabilities,¹¹ and so failure to outlaw discrimination or provide reasonable accommodation is therefore a violation of this right, although sadly this occurs frequently even within EU countries.¹⁷ Finally, women with disabilities are a diverse group, including women with different impairment types who need different types of adjustment (eg physical accessibility, simplified communication). Using a person-centered care approach (ie catering for the needs of the person as a whole),¹⁸ and thereby designing cervical screening services around the health-care needs of individuals will make services more accessible for women with disabilities, and also will likely improve them for all (eg minority language speakers).

Consequently, the aim of this paper is to provide an overview of the relevant literature and create principles for clinicians on cervical screening for women with disabilities. In this article we will therefore review (1) barriers faced, (2) gaps in cervical cancer screening, (3) existing guidance, and (4) propose principles of good practice for disability inclusive cervical cancer screening.

Methods

Overview

We undertook a scoping review of the existing literature to summarise key barriers to cervical cancer experienced by women with disabilities. We updated a systematic review of the association of disability with cervical cancer screening.⁸ We then searched the grey literature to identify guidance on the inclusion of women with disabilities in cervical screening programs and identified good practice examples. Finally, we formulated principles for clinicians on how to provide disability-inclusive cervical screening, based upon the above information and with our expert knowledge.

Definitions

Disability is conceptualized in this review according to the UN Convention of the Rights of Persons with Disabilities definition, as given above.¹¹ Disability therefore arises as a result of both bodily impairment, and personal and environmental barriers, and manifests as difficulties with participating. Eligible disability measures will therefore relate to presence of impairment (eg visual impairment) or difficulties with activities and participation (eg difficulties walking or communicating).

For the purpose of this paper, we refer to “women” and “women with disabilities” seeking cervical cancer screening. We acknowledge that trans men and other people who are gender diverse may have a cervix and therefore will require cervical cancer screening and have the right to access these services. Indeed, they are likely to face additional and complex barriers to seeking cervical cancer screening and so will need specific and targeted attention and interventions to address this inequity.¹⁹ However, we prefer to use the term “women” rather than “people” for clarity in public health messaging and to reflect the current numerical reality that the vast majority of people with a cervix identify as women.

Reviews of the Literature

We undertook a scoping review of barriers to accessing cervical cancer screening by women with disabilities. We ran a PubMed search on December 6, 2023 with the terms “cervical cancer” AND “screening” AND “disab*”. We included qualitative or quantitative studies on this topic published since 2000 in English, but from any part of the world. One researcher (HK) screened the titles and abstracts to identify eligible studies. Another researcher (SR) read the identified papers, and identified additional papers through reference searching and expert knowledge of the literature, and narratively summarized the findings in core themes.

A systematic review had been undertaken and was published in 2022, including two of the authors (HK and FA).⁸ This review was updated by identifying additional eligible studies from the above PubMed search (ie quantitative studies that compared cervical cancer screening – Pap smear or visual inspection – uptake/receipt of women with disabilities to those without disabilities, age 18–70 published after 2011), and scanning the references of a recently published review on the topic.⁹ Papers were excluded if they were not in English, reported findings from qualitative studies or were not peer-reviewed. Estimates were pooled to estimate the odds ratio of cervical cancer screening comparing women with and without disabilities. The pooled estimate was calculated using a random effects model and heterogeneity across analyses was assessed using the I^2 statistic.

A Google search was undertaken to identify protocols or guidance for the conduct of cervical cancer screening. These documents were searched to identify whether there was any mention of women with disabilities, and if so, key points and examples of good practice were noted.

Finally, the researchers (who included a public health consultant, and someone with lived experience of disability) then formulated principles for improved access to cervical screening based upon the identified barriers, existing recommendations and suggestions, and good practice examples. The Missing Billion Disability Inclusive Health Framework was used to guide the formulation of the principles, as it provides a structure for how components of the health system can be strengthened to improve access to health care for people with disabilities (Figure 1). These principles were mostly focussed on clinicians, and so addressed the service delivery components of the framework. We made an emphasis on using the “twin-track” approach in this guidance, emphasizing the need both to include women with disabilities in cervical cancer screening services and emphasizing where they may need targeted interventions.

Results

Barriers to Cervical Cancer Screening Experienced by Women with Disabilities

We screened 246 titles, from which we selected five papers that addressed this topic. A further 10 studies were identified that were deemed relevant, through reference tracing, or knowledge of the literature.

The barriers to cervical cancer screening among women in general are well understood, including lack of time, lack of information, feeling embarrassed or shy about screening, and fear that screening would be painful.^{21,22} Women with

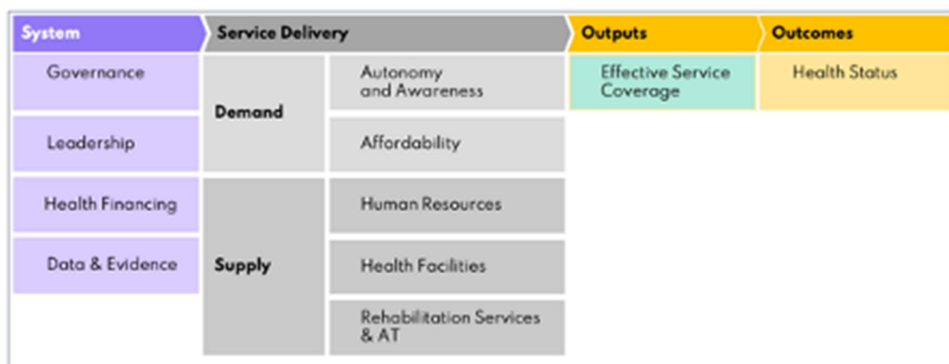


Figure 1 The Missing Billion Health System Framework.

Notes: Reprinted from The Lancet HIV, Volume 9/ Edition 4, Kuper H, Heydt P, Davey C. A focus on disability is necessary to achieve HIV epidemic control, pages e293–e298, copyright 2022, with permission from Elsevier.²⁰

disabilities may experience all these barriers, but in addition papers included in the review show that these barriers are further enhanced or there may be additional barriers on the basis of their disability. Disability-specific barriers generally fall into three categories: (1) knowledge and autonomy; (2) logistics; and (3) stigma and fear.

First, the review of the literature showed that women with disabilities frequently have less knowledge and awareness about screening for cervical cancer, which hampered their ability to decide to take part in screening.^{23–27} Lack of access to information is a critical barrier, as information is often not available in accessible formats (eg braille, screen-reader compatible, easy read, etc) and so does not reach all women with disabilities.²⁸ Furthermore, information available is often only focused on the experience of women without disabilities, and there was little information targeted to women with disabilities.^{28,29} Several studies also noted that, for women with intellectual disabilities, living in a care home was associated with higher rates of screening as family members themselves acted as barriers to screening. For example, one study explored family caregivers of women with intellectual disabilities perspectives of the barriers and found that many did not take their relative for screening because they perceived it was unnecessary or that it would be painful.³⁰

Second, logistics are a substantial barrier for women with disabilities to undergo cervical cancer screening, which may reduce the ability to access services or create uncomfortable experiences during screening.²⁵ Women with disabilities reported substantial difficulties organising appointments at a time that was not only convenient for them, but also where they had the appropriate support person to attend with them.²⁵ This issue was compounded by the fact most facilities do not have staff who are adequately trained to provide support (eg safe transfer techniques or sign language interpretation),³¹ and there was little flexibility to reschedule appointments if care fell through.²⁵ Moreover, several studies noted that accessible transportation and inaccessible health facilities presented further barriers to accessing cervical cancer screening.^{25,26,29} For example, a UK survey of women with physical impairments showed that only 64% of their GP clinics had wheelchair access and very few had public information about their accessibility.³² Inaccessible equipment is another concern highlighted by the survey – with reports by women with physical impairments of not being able to access the examination table, or physically comply with screening requirements (eg putting legs in stirrups). Health care professionals also lacked training on how to offer alternative screening approaches in these situations. Finally, costs associated with accessing cervical cancer screening were another barrier, particularly in settings such as the United States, where women faced particularly high costs for screening because of a lack of health insurance.^{29,31}

Third and finally, women with disabilities faced particular barriers in accessing cervical cancer screening because of stigma, fear and anxiety. Stigma from health providers was one of the most prominent reported barriers in this grouping, as women with disabilities regularly reported not seeking screening because of previously poor experiences with health providers,^{31–33} or because physicians erroneously assumed women with disabilities were asexual and therefore did not require screening.^{29,30,33} Some studies also suggested physicians avoided referring women with intellectual disabilities for screening because they perceived the extra steps required (eg explanation, sedation, longer appointment time, etc) to be challenging to conduct.³⁴ The literature also highlighted that women with disabilities experienced fear or anxiety about screening.²⁷ Several studies noted women with disabilities did not seek screening because they felt it would be uncomfortable or embarrassing.^{26,29} In contrast, a positive experience of the quality of the cancer screening was associated with an increased likelihood of engaging in cervical cancer screening for women with disabilities.³⁵

Inequalities in Cervical Cancer Screening Uptake for Women with Disabilities

Our search identified fifteen potentially eligible titles, of which four were included in the updated review (Table 1 and Figure 2). An additional eligible study was identified through referencing tracking. In total, we identified five new studies comparing cervical cancer screening uptake for women with and without disabilities, in addition to the 14 from the 2022 systematic review on this topic (search conducted 2021).⁸ All of the studies were undertaken in high income settings, including USA (n=9 studies), two in each of Canada, UK, Sweden, and South Korea, and one in each in Israel, and Taiwan. Most of the data came from routine electronic health records or existing registers. Seven studies focussed on a range of disability types or all disability, and other frequent disability types were psychosocial (n=6) and intellectual and developmental disability (n=4). All but two studies showed a lower uptake of cervical cancer screening among women with disabilities. One study³⁶ found that cervical screening uptake was significantly higher among women with

Table 1 Studies Included in the Systematic Review of Screening Uptake by Disability Status

Author, Year	Country	Data Source	Disability Type	Percent of Eligible Women with Disabilities	Uptake Women with Disabilities	Uptake Women Without Disabilities	Adjusted OR
Abrams, 2012 ³⁶	USA	Medicaid records	Psychosocial	NR	25%	18%	1.46 (1.36–1.57)
Baruch, 2022 ³⁸	Israel	Health records of HMO	Physical	1.7%	57%	63%	0.83 (0.79–0.88)
Brown, 2016 ³⁹	Canada	Clinical record from provincial database	Intellectual and developmental	NR	68%	77%	0.61 (0.58–0.65)
Chen, 2023 ⁴⁰	Taiwan	Linked registers	Any	NR	17%	22%	0.74 (0.73–0.76)
Cobigo, 2013 ^{41,a}	Canada	Clinical record from provincial database	Intellectual and developmental	NR	34%	67%	0.21 (0.20–0.21)
Eriksson, 2019 ^{42,*}	Sweden	Three linked regional health registers	Psychosocial	NR	86%	89%	0.98 (0.97–0.98)
Horner-Johnson, 2015 ^{43,a}	USA	Medical Expenditure Panel Survey from the Agency for Healthcare Research and Quality	Functional	NR	Rural: 77%	84%	0.69 (0.59–0.81)
					Urban: 82%	87%	0.78 (0.87–0.96)
Hu, 2023 ⁴⁴	Sweden	Linked registers	Psychosocial	13.3%	68.3%	71.2–71.4%	0.95 (0.95–0.95)
Ko, 2011 ^{45,a}	South Korea	Korean National Health and Nutrition Examination Survey	Physical and psychosocial	4.0%	>30 years: 29%	45%	0.71 (0.41–1.22)
					>40 years: 23%	43%	0.52 (0.27–0.98)
Kushalnagar, 2019 ^{46,a}	USA	Health Information National Trends Survey	Hearing	NR	78%	85%	0.71 (0.56–0.86)
Murphy, 2021 ^{47,a}	USA	MarketScan commercial insurance administrative claims	Psychosocial	16.8%	52%	61%	0.80 (0.80–0.81)

(Continued)

Table 1 (Continued).

Author, Year	Country	Data Source	Disability Type	Percent of Eligible Women with Disabilities	Uptake Women with Disabilities	Uptake Women Without Disabilities	Adjusted OR
Orji, 2023 ⁴⁸	USA	Behavioral Risk Factor Surveillance System (BRFSS)	Sensory, cognitive or physical	NR	Cognitive: 56%	55%	any disability (AOR=0.95, 95% CI=0.88, 0.97), physical disability (AOR=0.96, 95% CI=0.80, 0.98), and ≥2 disabilities (AOR=0.88, 95% CI=0.78, 0.97)
					Sensory: 50%		
					Physical: 48%		
Osborn, 2012 ^{49,a}	UK	The Health Improvement Network UK primary care database	Intellectual	NR	68%	85%	IRR = 0.54 (0.52–0.56) *
Shin, 2018 ^{50,a}	South Korea	Two linked databases (disability, cancer screening)	Physical and psychosocial	4.0%	54%	60%	0.71 (0.71–0.72)
Steele, 2017 ^{51,a}	USA	National Health Interview Survey	Any disability	11.9%	72%	82%	0.77 (0.60–0.99)
Weitlauf, 2013 ^{37,a}	USA	Electronic record from the VHA National Patient Care Database	Psychosocial	50.7%	n/a		Depression: 1.05 (0.99–1.12)
							PTSD: 1.14 (1.06–1.22)
Woodhead, 2016 ^{52,a}	UK	Electronic health record from the South London and Maudsley NHS Trust	Psychosocial	5.2%	80%	78%	0.35 (0.29–0.42)
Xu, 2017 ^{53,a}	USA	South Carolina Medicaid Claims	Intellectual	NR	64%	81%	Full adherence: 0.17 (0.16–0.19) Partial adherence: 0.37 (0.34–0.40)
Zanwar, 2022 ⁵⁴	USA	Medical Expenditure Panel Survey	Any disability	15.60%	82%	89%	P<0.001

Note: ^aIncluded in Previous review.⁸

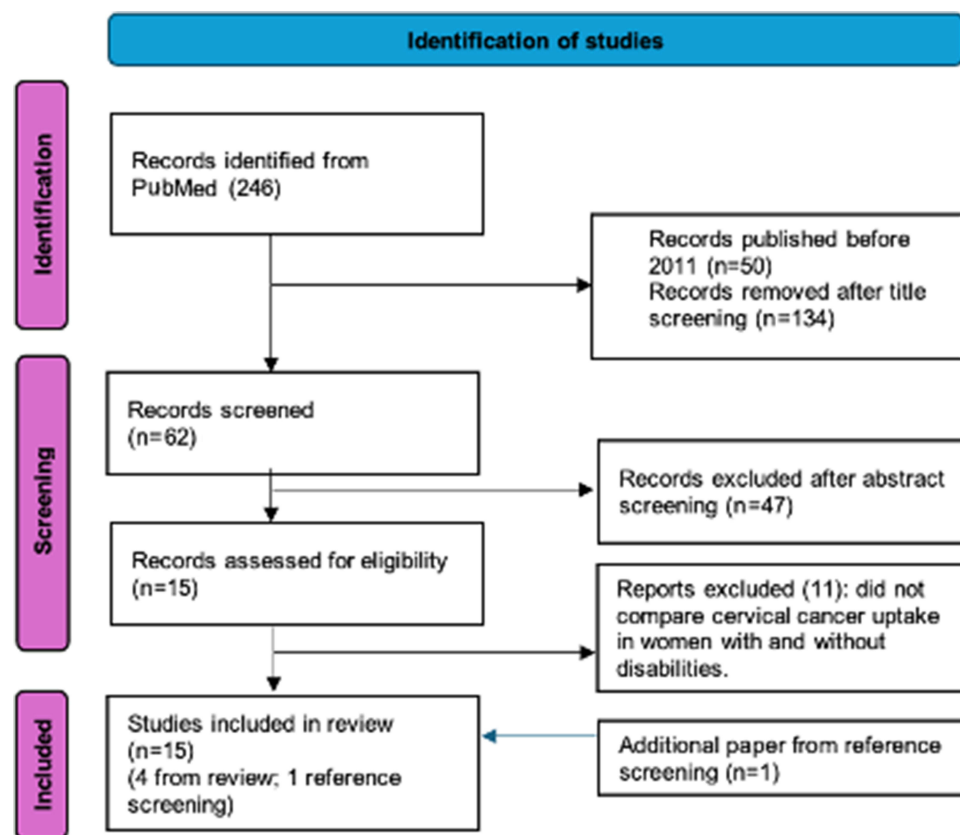


Figure 2 Flowchart showing identification of studies.

disabilities compared to those without ($RR=1.46$, $95\%CI:1.31-1.62$), while as second found it was higher among women with PTSD.³⁷

The meta-analysis showed that across the studies women with disabilities were substantially less likely to have received cervical cancer screening ($RR=0.65$, $0.50-0.84$), although there was high heterogeneity in the model (Figure 3). These overall patterns conceal variation by disability type and other characteristics, which likely contributes to the high levels of heterogeneity observed. For instance, data from Taiwan showed that coverage of screening reduced by severity of disability, and women with intellectual and developmental disabilities were particularly likely to be left behind in terms of screening ($OR: 0.38$, $0.36-0.40$) compared to, women with visual impairment (0.78 , $0.74-0.83$) or hearing impairment (0.95 , $0.91-0.99$).⁵⁵

Existing Guidance on Inclusive Cervical Cancer Screening

Our scoping review indicates that, in general, guidance documents on cervical cancer screening are not adequately providing information on how to improve access for women with disabilities.

Many guidance documents on cervical cancer screening do not mention disability at all (eg guidance from the British Gynaecological Cancer Society,⁵⁶ American Cancer Society,⁵⁷ American Academy of Physician Assistant,⁵⁸ Canadian Task Force on Preventive Health Care).⁵⁹ The WHO guideline for screening and treatment of cervical pre-cancer lesions for cervical cancer prevention published in 2021 includes only one mention of disability, but only in terms of disability as a consequence of cervical cancer.⁶⁰ In other guidance documents, there is brief acknowledgment of people with disabilities, for instance, that they may require additional support or consideration, such as for accessible information (eg National Cervical Screening Programme Policies and Standards New Zealand).⁶¹ The US Preventive Services Taskforce recommendation statement on cervical cancer screening merely acknowledges that there are data gaps for screening of women with disabilities and that incidence and mortality from cervical cancer higher in this group.⁶² Other

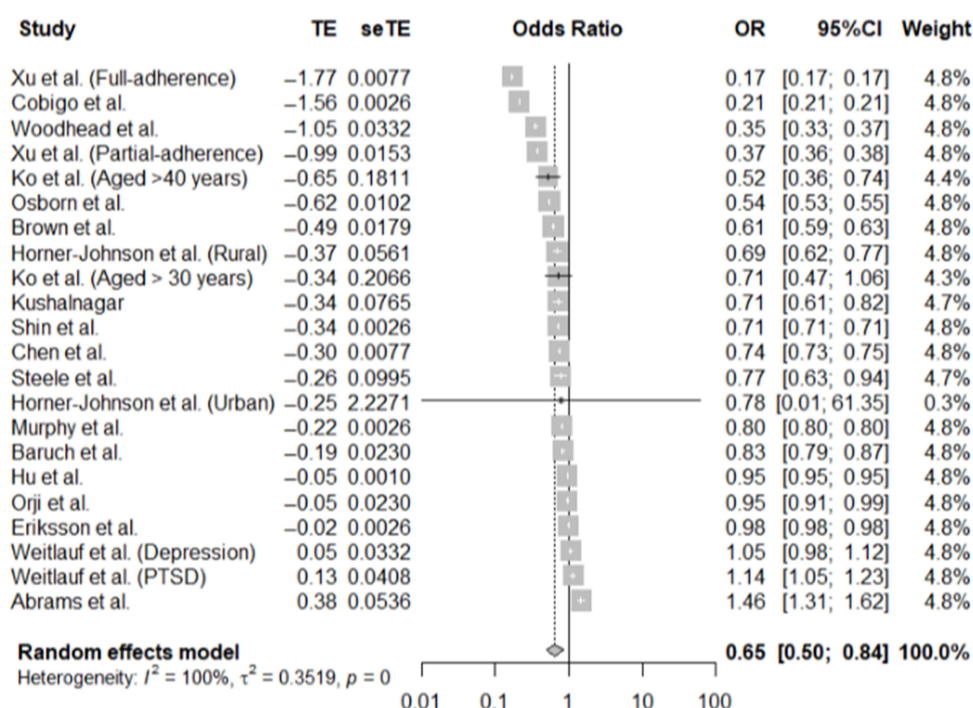


Figure 3 Pooled adjusted odds ratio estimates of cervical cancer screening uptake by disability status.

documents make limited, but more practical, mentions of disability. The new EU approach on cancer screening recognizes the specific needs of people with disabilities and that they may require support or assistance to access treatment or adapted clinical facilities, and specifies the requirement that “clinical facilities for cancer screening are suitable for persons with disabilities”.⁶³ Moreover, the Australian National Cervical Screening Program highlights that women with disabilities need cervical cancer screening, and encourages women to disclose their disability at the time of booking, so that extra support to do the cervical screening test can be arranged when needed.⁶⁴

There were some good practice examples of guidance documents on how to improve inclusion of women with disabilities in cervical cancer screening. The Australian Government has produced a toolkit to encourage cervical screening for people with disabilities.⁶⁵ It includes a range of resources for patients and providers, and suggestions for how to encourage uptake. The UK’s National Health Service (NHS) has produced guidance on “Supporting women with learning disabilities to access cervical screening”.⁶⁶ It includes resources for health professionals and patients, tools (eg easy to read invitation letter template) and suggestions on ways to overcome barriers to screening (eg offering longer appointments). Public Health England has a specific report on making reasonable adjustments to cancer screening for people with learning disabilities.⁶⁷ They provide guidance on issuing informed consent before screening, including consideration of capacity to consent, and provide examples of reasonable adjustments and case studies in cervical cancer screening. Other regional and local NHS guidance documents on cervical cancer also include a focus on women with learning disabilities, such as reaffirming their right to screening, challenging assumptions that they are sexually inactive, and explaining how to make simple language information available.^{68,69} They also include practical tips to support women with disabilities (eg familiarizing them with the screening room and equipment).

There are also more generic guidance documents, not specifically related to cervical cancer, which promote the inclusion of people with disabilities in all services. For instance, the UK has a statutory requirement through the Equalities Act 2010 for public sector organizations to adapt their approach or provision so that people with disabilities are not disadvantaged compared to those without disabilities. Similarly, the Americans with Disabilities Act in the US, under which health care organisations are covered, prohibits discrimination against people with disabilities. There are also anti-discrimination laws in the European Union, Australia, New Zealand, and Canada that protect citizens with disabilities, and their rights to access equitable health care.

Principles for Inclusion of Women with Disabilities in Cervical Cancer Screening

The review on barriers and guidance documents were used to formulate key principles, in terms of improving (1) autonomy, awareness, and affordability, (2) human resources, and (3) health facilities.

Autonomy, Awareness and Affordability

Women with disabilities should make their own decisions about cervical cancer screening, be aware of their rights and options and afford service access.

Women must have information on why, where and how to access cervical cancer screening. Information must therefore be provided in different formats, depending on impairment type (eg Easy Read or Audio described). It may also be important to include pictures of women with disabilities in mainstream cervical cancer information to emphasize that this service is also relevant to them. Women with disabilities may be reliant on family members or carers to support them to access cervical cancer screening, particularly if they live in residential facilities. It may therefore also be helpful to offer information to carers on the importance of screening. Options to book appointments also need to be accessible (eg online services), with alternative modes offered (eg also phone booking).

Improving information may be insufficient to improve autonomy and awareness about cervical cancer screening. Health professionals could also invite women with disabilities for a preliminary visit, as an opportunity to explain the benefits of screening, or to help familiarize the women with the cervical screening room and equipment (eg showing her a speculum, demonstrating the position she will need to adopt to allow examination). Similarly, outreach visits can be arranged by nurses to women with disabilities to explain the need for screening, potentially with aids (eg doll). Carers can also help provide information on the best modes of communication (eg the words the woman uses for vagina), and the woman's needs and preferences.

A critical element within autonomy is informed consent. The purpose of consent includes education for the patient on the risks, benefits and options available for a procedure. Ensuring consent is affirmative, active, and accessible is crucial, and this requires consideration of a patient's individual capabilities and perspectives. In particular, providers must take consent in an accessible format, depending on the individual's impairment (eg written or signed for women with hearing impairments, re-explaining points if necessary). Providing co-produced materials will also enhance the appropriateness of the information used.⁷⁰ Where the woman does not have the capacity to consent, someone else "responsible" will have to do so on her behalf, or the family and health-care worker can use a best interest decision-making process to agree how to proceed. In some cases, an independent advocate may be provided to ensure the best interests of the individual are fulfilled.

Communication to promote uptake and obtain consent are not enough. Women with disabilities may benefit from increased communication to explain each part of the procedure and what is happening, to maintain their autonomy. For example, a woman with a visual impairment may find it difficult to understand the required position or process without the provider describing each step of the exam or a woman with developmental disabilities may be more relaxed with more information about the sensory aspects of each step.

In many countries, cervical cancer screening is provided free or under health insurance. Despite a free service, there remains inequitable access, with lower uptake among people living in more deprived areas, or of lower socioeconomic position, often intersecting with women with disabilities. Transport may be a key affordability issue that needs to be addressed, particularly for women with physical impairments. Options here include providing transportation assistance or collaborating with local transportation services. Another option is for outreach services for those where a home visit from a trained sample taker may overcome several access barriers.^{32,71} Measures to ensure women with disabilities are covered by health insurance, and that insurance covers cervical cancer screening is also important in some settings to address affordability.

Human Resources

The health-care workforce is knowledgeable about disability and has the skills and flexibility to provide quality cervical cancer screening to women with disabilities.

Health providers have the obligation to make reasonable adjustments for people with disabilities to ensure that they are not disadvantaged when seeking care (eg UK Equality Act 2010). A first step is that health providers have the appropriate

knowledge, attitudes and skills to make these adjustments. A key need is to offer alternative modes of communication (eg simplified language, pictorial guides, provision of sign language interpretation). Moreover, the procedure for the screening may need to be modified, such as providing assistance with dressing/undressing, offering alternative ways for performing the speculum examination (eg using different positions, which may require assistance), and using safe transfer procedures for women with physical impairments. Here, the health-care worker must acknowledge the patient's knowledge of her disability, and ask about preferences. Where appropriate, it is helpful to ask the carer about the needs and preferences of the woman during the screening. The health-care worker also needs to be aware of specific risks for women with disabilities during screening and how to detect and manage these, including distress, pain, discomfort, or side effects (eg rare occurrence of hypertension during the screening of women with spinal cord injuries).⁷²

Health workers may also need flexibility to be able to provide quality services. For instance, provision of longer appointment times may be an important accommodation to make accessing cervical cancer screening easier for women with disabilities,³² as the screening may take longer and to give the woman time to relax and adjust to her environment. Given the barriers experienced by this population, providers should consider whether home visits or self-screening tools may provide a more conducive environment for women with disabilities to access screening. Flexible appointment scheduling may also be helpful, as already discussed, particularly given transportation or other support coordination issues (eg interpreter availability). It is also useful to identify at the time of booking whether patients have difficulties communicating (eg due to hearing or intellectual impairment) so that alternative communication modes are prepared (eg sign language interpreter) and potentially additional assistance.

Consequently, health-care workers require training on disability so that they have the right knowledge, skills and attitudes to provide high quality services to people with disabilities.^{70,73} The curriculum should include training on: awareness of rights and needs of women with disabilities with respect to cervical cancer screening, the ability to use reasonable accommodations, alternative communication options and approaches to taking consent for people with intellectual impairments. Information to aid stigma reduction should also be included, such as challenging assumptions that women with disabilities are asexual and therefore do not require cervical cancer screening. Training should also provide an opportunity for people to discuss issues and concerns and should ideally in-person interactions with people with disabilities. Health-care workers also need resources such as toolkits to support uptake of cervical cancer screening by women with disabilities. For instance, these could include resources on capacity assessment guidance, Easy read invitation letter template, and signpost to good practice examples.

Health Facilities

Principle: Health-care facility infrastructure is accessible for people with disabilities.

The legal obligation to make health services accessible is almost universal, and most countries will have accessibility standards to which health facilities must comply. Accessibility of facilities encompasses physical accessibility (eg ramps, sufficiently wide doors), but also accessibility for people with hearing impairment (eg hearing loops, signage), visual impairments (eg braille signage, good lighting) and intellectual/developmental impairments (eg quiet spaces). Accessibility of equipment is also important for provision of inclusive cervical cancer screening, which may include provision of hoists, adjustable couches and stirrups, and staff must be trained in the use of this equipment. Making requirements for accessibility is insufficient – and plans should be in place for routine auditing of the accessibility of facilities with appropriate follow-on actions if these standards are not met.

Alternative options may still be needed to be put in place, despite efforts to make facilities accessible. For instance – people with certain physical impairments may be better served by an alternative venue that can cater to their particular needs. Moreover, in rare situations women with intellectual disabilities may need anesthesia or sedation to complete the screening, which may only be available in certain services. As already discussed, home-based screening or community outreach may also be an option, potentially without the need for speculum examination.⁷⁴ For instance, the woman may self-collect samples, potentially with assistance from a carer or health professional.

Discussion

Women with disabilities face a range of barriers in accessing cervical cancer screening, and as a result have lower levels of screening uptake. This lower coverage likely contributes toward their higher death rates from cervical cancer and may make it challenging to eliminate cervical cancer as a public health problem. Guidance on making cervical cancer screening is currently lacking, notwithstanding the few good practice examples that exist. Improving the inclusion of women with disabilities cervical cancer screening will require interventions to promote autonomy, awareness and affordability of services by women with disabilities, as well as changes for health workforce and facilities.

There are some important, additional considerations for making services inclusive. Changes needed to improve delivery of cervical cancer screening go beyond the scope of influence of clinicians, and also require systemic building blocks to be in place. These include the existence of governance (ie laws and policies to support cervical cancer screening for women with disabilities), leadership on disability in the Ministry of Health and other health sector structures, financing to support inclusive service delivery, and data and evidence to identify gaps and indicate best practice. These components were not specifically assessed in this review as they were more focused on the clinician, yet there are clearly key gaps, particularly in low- and middle-income countries where there is higher mortality from cervical cancer.¹ For instance, there is a lack of good evidence base of what works to improve access to cervical cancer screening, or indeed other sexual and reproductive health services, for women with disabilities.⁷⁵ A small trial in the USA showed that a health education intervention had some impact on improving knowledge on cervical cancer screening for women with intellectual disabilities.⁷⁶ A counselling intervention was also associated with a modest improvement in cervical cancer screening uptake among women with intellectual disabilities in the UK.⁷⁷ A trial in the USA demonstrated that a 90-min, small-group, participatory workshop with 6 months of structured telephone support, increased uptake of cervical cancer screening.⁷⁸

Addressing inequities in cervical cancer screening is an important step toward closing the mortality gap and ensuring rights to health care are respected. However, there are also other influences on the disparities in mortality such as the choice of treatment and stage of diagnosis. A study from Korea showed that women with disabilities were less likely to receive surgery (AOR=0.81, 95% CI 0.73–0.90) or chemotherapy (AOR=0.86, 95%CI: 0.77–0.97) even after adjusting for sociodemographic factors, comorbidity and stage at diagnosis. Disparities in outcomes and quality of services for people with disabilities described here for cervical cancer are also observed in a range of other cancer types, indicating consistently worse outcomes for people with disabilities,⁷⁹ and this issue needs urgent attention. Moreover, there are also likely to be disparities in preventive care, such as access to HPV vaccines for women with disabilities.

There are also some limitations, as well as strengths, to our review paper. We took a holistic and broad assessment of barriers, coverage and guidance. Yet, a scoping review, rather than systematic review, was undertaken both to identify barriers and guidance on screening. Furthermore, we undertook single screening and data extraction for the scoping review. We updated a systematic review on coverage of cancer screening, but there were still large gaps (eg inclusion of low resource settings), and inconsistency in the measurement of disability which made comparison difficult. There was insufficient data to disaggregate screening coverage by disability type, although there are likely to be differences between certain groups. There is also a lack of data for LMICs, and policy and program requirements may be different in those settings. Our review of guidance documents is unlikely to be comprehensive, and therefore should be taken as illustrative, and existing recommendations focussed frequently on women with intellectual impairments rather than women with disabilities more broadly. Principles for inclusion were based upon our perspective and review of literature, but were not formulated through a formal process. A formal process to develop and implement guidelines on making cervical screening inclusive of women with disabilities, in collaboration with women with disabilities themselves, is an important next step.

In conclusion, women with disabilities should be an important priority group in cervical cancer screening. Guidelines should include specific mention of this group, including consideration of their need for screening, as well as reasonable adjustments. Guidelines should be holistic, and not focus on only one group (eg women with intellectual impairments). Promoting inclusive screening will likely contribute toward closing the cervical cancer mortality gap experienced by women with disabilities and fulfill their right to health. Moreover, the changes described are likely to improve screening access for all women.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

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