

# IMPROVING THE UPTAKE OF CERVICAL SCREENING FOR PATIENTS WITH A LEARNING DISABILITY (LD) IN BSW

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This toolkit, which has been developed by a GP for primary care professionals, offers a simple guide to delivering an enhanced cervical screening service for patients with a learning disability.

In BSW 40% of this population are overdue their cervical screening. This resource supports practices to deliver a range of evidence based reasonable adjustments in order to address the health inequalities gap experienced by patients with LD .

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# **Using this toolkit to enhance your Cervical Screening Service for LD patients at your practice will help you to:**

- Meet your legal obligation to offer adequate reasonable adjustments
- Meet your QOF targets
- Reduce the health inequalities gap experienced by people with LD
- Reduce rates of cervical cancer aiming to eliminate cervical cancer by 2040

# CONTENTS

## Toolkit

A guide to delivering your own intervention

## Supporting slides:

What is the background to the problem?

Why does this matter?

What does the evidence tell us?

Enhanced Cervical Screening Service at Trowbridge Health Centre

Kotter methodology for leading change

Reflections

Useful links

**TOOLKIT FOR DELIVERING  
+ YOUR OWN ENHANCED  
◦ CERVICAL SCREENING  
SERVICE FOR LD PATIENTS**

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- The aim is that the supporting slides leave you feeling inspired and motivated to make some changes at your practice to offer a similar Enhanced Cervical Screening Service for LD Patients.
  - This will enable you to meet your legal obligation to offer adequate reasonable adjustments, meet your QOF targets, help reduce the health inequalities gap experienced by people with LD and help to eliminate cervical cancer.
  - This guide is informed by the lessons learned from my own experiences and modelled on the Kotter methodology for leading change (see useful links).

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### **Step one- what is the data from my practice?**

Carry out a search on System One to identify how many of your LD population who are eligible for cervical screening are currently overdue their screening test.

You can also request your practice data from ICB Population Health Intelligence by emailing [bswicb.bswanalyticsrequests@nhs.net](mailto:bswicb.bswanalyticsrequests@nhs.net) and marking your email "FAO BSW ICB Population Health Intelligence Lead".

### **Step two- what are my practice already doing?**

Is there a designated member of the admin team who looks after the LD register? If so, what are they currently doing to support this population of patients? Your practice should already be offering some reasonable adjustment. Identify what these are and what the systems are in place for delivering these.

### **Step three- identify and work with stakeholders**

#### **Key stakeholders:**

1. The patients this service supports and their family/carers. Find out from this group what their experiences have been and what they think would make things better in order to co-develop a service that really meets your local patients' needs.
2. All the staff involved with developing and delivering this service.

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## **Wider stakeholders:**

These could be any organisation or group who have an interest in, and may be able to support, your Enhanced Cervical Screening Service and its outcomes. These could include:

3. BSW ICB Health Inequalities Team
4. BSW ICB Learning Disability and Autism Team
5. South West Screening and Immunisations Team
6. Local council teams
7. Local charity organisations
8. Local community groups
9. Local residential services

These teams/groups may be able to support in a number of ways and can contribute to joined up working with similar projects across your region. You might be surprised at how interested they are to work with healthcare professionals from primary care whose time is often very limited.

It is worth reaching out to your Stakeholders early on in the process and keeping in touch regularly.

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## **Step four- what is our vision for the service?**

Identify the changes you want to introduce to your practice. This should ideally be co-developed with your key stakeholders and informed by the evidence. The 'Cervical Screening in Primary Care: Supporting People with Learning Disabilities Resource Pack' (see useful links) has further information on possible interventions.

Clearly define your vision of what your Enhanced Cervical Screening Service for LD patients looks like.

## **Step five- who are my champions for change?**

You will not be able to initiate meaningful change on your own.

Discuss your proposed changes with all the partners and managers at your practice early on. Doing this face to face is always best where possible - asking for a slot on the agenda at the practice meeting offers a great opportunity to do this.

Identify team members who share your motivation for initiating this change and work closely with them.

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## **Step six- get the whole team on-board**

Generate a sense of urgency around the problem to help to motivate the whole team.

Present your vision of the service to the team and generate an agreed strategy on how this will be achieved. Doing this as a team will help to secure partner buy-in to your strategic vision.

## **Step seven: Identify any quick wins**

Consider what change(s) can be easily and quickly implemented, perhaps by building on systems that are already well-established, to generate some short-term wins. This quickly makes the service better for patients and can energise staff to remain committed to your strategic vision.

## **Finally... Keep going!**

Driving change is hard work but keep persevering and you will make progress.

## **Feedback**

Please provide feedback on this toolkit and the service you have implemented to:

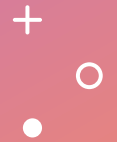
[bswicb.ldan@nhs.net](mailto:bswicb.ldan@nhs.net)

**WHAT IS THE  
BACKGROUND TO THIS  
PROBLEM?**



- NHSE aims to eliminate cervical cancer by 2040.
- The national standard for cervical screening coverage is 80%. In England in 2023 67.2% of women aged 25 to 49 had an adequate screening test recorded in the previous 3.5 years and 74.7% of women aged 50 to 64 had an adequate screening test recorded in the previous 5.5 years (Cervical screening: data and research - GOV.UK).
- Screening rates are currently on a downward trajectory.
- The cervical cancer elimination strategy comprises of three pillars all of which need to be met:
  1. Prevention – HPV vaccination
  2. Early detection – Screening
  3. Timely treatment
- We recognise that our LD population experience a significant health inequalities gap. The LeDeR review in 2022 identified that 42% of LD deaths were due to an avoidable cause. The median age of death for those whose deaths were reported was 62.9 years of age.
- Across BSW an average of 40.6% of LD patients are currently overdue their cervical screening.

**WHY DOES THIS  
MATTER?**





## The Quality and Outcomes Framework guidance for 2024/25 states:

- It is a statutory requirement under the Equality Act 2010 that public sector agencies make 'reasonable adjustments' to their practice that will make them as accessible and effective as they would be for people without disabilities.
- Reasonable adjustments include removing physical barriers to accessing health services, but importantly **also include making whatever alterations are necessary** to information, policies, procedures, staff training, communication interventions and service delivery **to ensure that they work equally well** for people with learning disabilities.

### **Is your practice currently doing enough to meet this requirement?**

This toolkit offers a step-by-step guide to improve your offer of reasonable adjustments for your LD patients to access their Cervical Screening Service.

**WHAT DOES THE  
EVIDENCE TELL US?**

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# BSW ICB data 09/24

This report was provided by the BSW ICB

This report includes those who are eligible, up to date, declined/unsuitable and overdue cervical screening and on the LD register

The searches created for this report have been modified from the Ardens SMI cervical screening searches. This report does not include 1 EMIS Practice (all other practices in BSW included).

Summary of grand total results:

- 1300 eligible patients
- 29.2% up to date with cervical screening
- 30.2% declined/ unsuitable
- **40.6% overdue cervical screening (range of 0-100% across individual practices)**

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# Interventions to improve uptake of cervical screening in women with learning disabilities: a rapid narrative review and synthesis by Dr Hannah Thornton, Public Health Registrar (full report in appendix A)



## Method



For this review, the PubMed database was searched using the following terms: (cervical) AND (learning disability\*) AND (cancer) 51 results. Studies included were published between 2019 and 2024, in English, in UK settings, and contained results from on real-world interventions to improve screening uptake in women with learning disabilities. Grey literature was also searched via Google.

## Results

52 papers were identified in the Pubmed search, of which 12 full texts were screened and 4 were included in the synthesis. A search of the grey literature identified three additional web publications with relevant material. The evidence demonstrates that multifaceted approaches are most effective in increasing cervical screening uptake among women with learning disabilities. We identified five key themes by which interventions were classified:

1. Educational Interventions such as tailored information and use of visual aids.
2. Healthcare Provider Training: Specialised training programmes for staff, inclusivity in screening from the outset, training staff on appropriate use of the mental capacity act.
3. Supportive Interventions around the appointment: enhanced appointment time, family and carer involvement, preparation and familiarisation, one to one support, creating supportive environments, improving physical access.
4. System-Level Interventions: flexible scheduling, system reminders, local education, guidance availability and effective joined up working between the patient, their carer, the GP, the local LD team and other services involved.
5. Policy and Advocacy: inclusive policies, public health campaigns.

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# Local qualitative data

I delivered an education session and held a focus group with LD women and their support staff at a local day center in Trowbridge where I learnt that their barriers to accessing screening included:

- A lack of understanding from the patients, their family members and their carers about why screening is advised when the individual is not known to be sexually active.
- Patients finding it challenging to contact the surgery by phone to book their appointment.
- A lack of continuity with familiar staff who the patient feels comfortable with.
- A lack of familiarisation opportunities.
- Apprehension and anxiety about the intimate nature of the screening test.

Subsequently two of these women successfully completed their cervical screening.

**OUR ENHANCED  
CERVICAL SCREENING  
SERVICE**

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## **We are delivering an Enhanced Cervical Screening Service for LD Patients at Trowbridge Health Centre. It takes an evidence-based multifaceted approach which offers reasonable adjustments from 4 of the 5 key themes identified in the literature review.**

1. A dedicated member of the admin team holds a list of all our patients on the LD register who are eligible for cervical screening and regularly identifies those who are currently overdue.
2. The team member contacts these patients and/or their carers directly as appropriate which overcomes the barrier of patients having to proactively respond to their screening letter.
3. The team member offers to book the patient into any available cervical screening clinic. This offers the flexibility to book the appointment around other important activities in the patient's week.
4. Patients are offered a double appointment of 40 minutes allowing more time for staff to explain the procedure, answer any questions, complete the screening test with appropriate consent and allow for a debrief at the end of the appointment.
5. Patients are advised that they can bring a carer or friend to the appointment if they would like to. They are also advised that they can bring a comforter or distractor. This helps to create a supportive environment.
6. The patient is sent an easy read guide to cervical screening in the post or electronically as preferred prior to their appointment.
7. A scheduled appointment reminder is sent out to the patient on the day of their appointment.
8. Our sample takers have received update training from the South West Screening and Immunisation Team on collecting cervical samples from patients with LD. This was recorded and is available to access on the BSW Training Hub website (see useful links).

**KOTTER  
METHODOLOGY FOR  
LEADING CHANGE**



## Dr Kotter developed the 8 steps for leading change as a model for producing lasting change:

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# REFLECTIONS



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There were several challenges to overcome to get our Enhanced Cervical Screening Service for LD Patients off the ground. Introducing change is not easy, especially within a short or restricted time frame, and I have not yet been able to do everything I hoped to do. In particular I have not yet found an adequate way to offer familiarisation opportunities to our LD patients. + ●

However we will continue to learn from what is working and not working for our patients, work on improving the service further and sharing this learning with others where possible.

It is important to create supportive communities of practice to assist similar work across the region. I am happy to be contacted by others who are planning or undertaking similar work to share my experiences and learning further.

Please email me at: [s.taylor9@nhs.net](mailto:s.taylor9@nhs.net)

# USEFUL LINKS





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# Patient Resources

- 1. Cervical screening: an easy guide  
CSP05\_easy\_guide\_to\_cervical\_screening\_June\_2024\_PDF.pdf  
(publishing.service.gov.uk)
- 2. Mencap: Cancer Screening Easy Read Information About Cancer and Cancer Screening  
| Mencap
- 3. Jodie's Story; a short film where Jodie explains how she attended her first cervical screening appointment after her GP practice made the right adjustments to make her feel more comfortable and confident. [https://youtu.be/zOq\\_a2BYERc](https://youtu.be/zOq_a2BYERc)

# Healthcare professional resources

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1. Quality Outcomes Framework 2024/25 ([england.nhs.uk](https://www.england.nhs.uk))
2. Learning from lives and deaths - People with a learning disability and autistic people (LeDeR) Action from learning report 2022/23  
20231019\_LeDeR\_action\_from\_learning\_report\_FINAL.pdf  
3. Tackling Health Inequalities | Seven Priorities For The NHS | The King's Fund ([kingsfund.org.uk](https://www.kingsfund.org.uk))
4. NHS England » NHS sets ambition to eliminate cervical cancer by 2040
5. Webinars and resources - [bswtraininghub.nhs.uk](https://www.bswtraininghub.nhs.uk)
6. The 8-Step Process for Leading Change | Dr. John Kotter ([kotterinc.com](https://www.kotterinc.com))
7. NHS England South West. Cervical Screening in Primary Care: Supporting People with Learning Disabilities Resource Pack. FutureNHS Collaboration Platform

# Appendix A

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## Interventions to improve uptake of cervical screening in women with learning disabilities: a rapid narrative review and synthesis by Dr Hannah Thornton

### Introduction

Women with learning disabilities are less likely to participate in cervical screening programs compared to the general population, which can lead to increased morbidity and mortality.

This literature review aims to identify and synthesise evidence-based interventions to improve uptake of cervical screening in women with learning disabilities in primary care.

### Methods

For this review, the PubMed database was searched using the following terms: (cervical) AND (learning disabilit\*) AND (cancer) 51 results. Studies included were published between 2019 and 2024, in English, in UK settings, and contained results from on real-world interventions to improve screening uptake in women with learning disabilities. Grey literature was also searched via Google.

All included papers were synthesised, and the key themes were summarised in this narrative review.

### Results

52 papers were identified in the Pubmed search, of which 12 full texts were screened and 4 were included in the synthesis. A search of the grey literature identified three additional web publications with relevant material.

The evidence demonstrates that multifaceted approaches are most effective in increasing cervical screening uptake among women with learning disabilities. We identified five key themes by which interventions were classified.

#### 1. Educational Interventions:

- Tailored Information: Providing accessible information tailored to the cognitive abilities of women with learning disabilities has been shown to improve understanding and willingness to participate in screening programs. Invitations to screening should be made by phone or in person, as well as by letter.
- Use of Visual Aids: Visual aids, such as diagrams and videos, convey the importance and process of cervical screening more effectively than text or discussion alone. Women reported not knowing what to expect or what the process would entail. Providing accessible information beforehand can improve uptake. Additionally, providing information about what happens after screening, and making sure that this is also in an accessible format, will support women to engage with any subsequent tests or treatment, whilst reducing anxiety. Specific suggestions include:

# Appendix A

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o “A leaflet that has pictures on, that I could actually explain along with the pictures of what it entails...”

o In addition to information on “the worst case scenario... Maybe a story of somebody that has had an abnormal result

o As well as a leaflet, methods which do not rely on the women reading where identified “including a DVD... something women focussed using pictures, signs and symbols (Makaton) where necessary”

o An opportunity to discuss cancer screening with someone not related to the care was also suggested: “I think maybe if there is more people coming in... and talking to women with ID and their carers and explain to them what it's about and how often they have it done and whatever”

## 2. Healthcare Provider Training:

- **Specialised Training Programs:** Training healthcare providers to communicate effectively with women with learning disabilities and to address their specific needs can increase screening rates. Programs that focus on sensitivity, patience, and the use of simple language are particularly effective.

- **Inclusivity from the outset:** Women with learning disabilities should not be excluded from cervical screening due to assumptions made about their disabilities, sexual lives or perceived difficulties obtaining consent. Assumptions of sexual inactivity by women with learning disabilities are raised in a number of articles, which refer to GPs views about the lack of sexual activity in women with learning disabilities. Articles published within the learning disabilities field show a different picture, and additionally show that women with learning disabilities are vulnerable and can be exposed to physically and emotionally abusive relationships.

- **Capacity:** Ensuring that clinicians know when to use the Mental Capacity Act checklist. For women with a severe learning disability, who do not demonstrate a capacity to consent to the procedure, the “best interest” option must apply.

## 3. Supportive Interventions around the appointment:

- **One-to-One Support:** Providing one-to-one support from a trained nurse or a support worker before, during and after the appointment can reduce anxiety and encourage participation .

- **Preparation:** Health professionals should work with the woman and if appropriate, her carer, to prepare her for her smear test, by arranging a visit to the clinic before the screening appointment or being shown the equipment that will be used.

- **Enhanced Appointment Time:** Allowing extra time for appointments to ensure that women with learning disabilities understand the procedure and feel comfortable can lead to higher screening uptake .

- **Family and Carer Involvement:** Involving family members and carers in the educational process and appointment can provide additional reassurance and motivation for women with learning disabilities. Discussion with the patient is also very important where possible, with one study reporting ‘There were multiple indications that family/paid care workers were making decisions on behalf of women with learning disabilities, with no evidence of previous discussion with them.’

# Appendix A

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- Creating supportive environments: Talking to women and their families/carers about sensory difficulties and how to overcome them is important for each individual. For example, one study reported “Some women with autism...tactile defensive issues, the smell, the curtains, the buzzing and the machinery. They just can't cope with it’. The literature also reports the use of psychological support to reduce anxiety. Additionally, there is consensus in the literature that offering a female clinician to do the smear test can improve uptake.

- Improving physical access: Consideration of physical disability and the need to use different height couches, different positions, hoists, domiciliary visits to do the smear test can help to improve uptake.

## 4. System-Level Interventions:

- Flexible Scheduling: Offering flexible scheduling options, including longer appointment times and choice of female healthcare providers, can accommodate the needs and preferences of women with learning disabilities .

- Reminder Systems: Implementing reminder systems, such as phone calls or texts, specifically tailored to women with learning disabilities, can improve attendance rates

- System working: Joint working with GP practices and women, their carers, and their specialist care team. Linking with local learning disability nursing teams to provide specialist support. Eligibility for the cervical screening programme must be a carefully made, multidisciplinary decision.

- Local education: introducing specific training as part of the local screening education programmes, which would include consent issues and ceased recall.

- Guidance: The NHSCSP Good Practice guidelines should be readily available in all practices and provider work places offering cervical screening. Easy read information packages should be made available to women with learning disabilities to help them to fully understand the procedure. (Example available from the Gloucestershire Learning Disability Health Facilitation Team – 07876 548827).

## 5. Policy and Advocacy:

- Inclusive Policies: Advocacy for inclusive healthcare policies that mandate reasonable adjustments for women with learning disabilities in cervical screening programs is crucial. Policies that recognise and address the barriers faced by these women can foster a more inclusive healthcare environment.

- Public Health Campaigns: Public health campaigns that specifically target women with learning disabilities and their caregivers, emphasising the importance of cervical screening and available support, can raise awareness and increase participation.

# Appendix A

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## References

Psycho-Oncology - 2019 - Byrnes - Attitudes and perceptions of people with a learning disability family carers and paid.pdf

watts-2013-access-to-cervical-screening-for-women-with-learning-disabilities.pdf

broughton-2002-a-review-of-the-literature-interventions-to-maximize-capacity-to-consent-and-reduce-anxiety-of-women.pdf

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1114982/>

<https://ghc.nhs.uk/files/cervicalscreening.pdf>

<https://www.gov.uk/guidance/cervical-screening-ideas-for-improving-access-and-uptake#women-with-specific-needs-or-with-disabilities>

<https://www.bmj.com/content/318/7182/536.3.full>



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# THANK YOU

For further information please contact:  
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