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Learning Disability Life Expectancy Report



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Voice It, Hear It

Community voices inspiring positive change to local support and services.

Voice it, Hear It is an engagement project that works with people aged 18+ living in Wiltshire to get involved in shaping the health and social care services they use.

We work with people with physical disabilities, sensory needs, mental health issues, learning disabilities, neurodiversity, long term conditions, complex needs, older people and people with dementia.

We also work alongside Wiltshire Council and the Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board (BSW ICB) and people living and working in Wiltshire to co-produce, co-design and co-develop health and social care services in Wiltshire.

Voice It, Hear It is a partnership project led by Community First, working with Wiltshire Service Users' Network, Wessex Community Action, Age UK Wiltshire, Alzheimer's Support and Celebrating Age Wiltshire.

Delivered by:



Funded by:



Introduction

Wiltshire Council Public Health has led a project, piloting at the Medley Day Centre health screening talks and packs with those who use the service. Voice it, Hear It aimed to explore how effective this had been and to explore issues surrounding access to health information and screening.

Current data shows that the life expectancy of individuals with learning disabilities is approximately 20 years shorter than that of the general population.

In doing this we were able to understand the experiences of health screening among people with learning disabilities, identifying where the process works well and where improvements can be made.

Engagement methods included art sessions, workshops, surveys, and educational talks on various health issues. All quotes included in this report are direct reflections from the individuals who participated.



Key Messages

The talks delivered by Public Health staff were well-received, leading to immediate and positive changes from some participants.

Participants reported that the discussions helped them better understand the importance of health screenings and encouraged proactive health behaviours.

Direct outcomes included increased engagement with personal hygiene, such as regular teeth brushing and hand washing, as well as an uptake in self-checks for testicular health following conversations around prostate and testicle screening.

Developing and Embedding Accessible Information:

The findings of this project support the need for health support and screening information to be consistently presented in clear, accessible formats. This practice should be embedded across various community settings to ensure everyone can understand and act on the information provided.

Enhancing Positive Experiences:

Providing sufficient time for individuals during screening appointments, along with opportunities to ask questions, significantly improves their experience. This approach helps make even invasive procedures more manageable and less intimidating.

Promoting Effective Communication:

Clear, open communication and the use of straightforward, appropriate language are essential in addressing myths and reducing confusion around healthcare and screenings. This helps build trust and understanding between healthcare providers and individuals, particularly those with learning disabilities.



Engagement Methods

The engagement aimed to gather diverse perspectives on the Wiltshire Council Prevention Strategy. We employed multiple methods to reach and engage participants:

- Surveys (online and paper)
- Focus groups with community members and service users
- Workshops to encourage group discussions and idea sharing
- Public promotion through social media, community newsletters, and online platforms

We promoted the Prevention & Well-being Strategy through our contacts and partner organisations and also utilised the wider Wiltshire Together network.

We worked with people with lived experience to create case studies that explain the three prevention approaches – primary, secondary and tertiary in everyday life and language. **See Appendix 1.**

We engaged people with lived experience to create an audio and video version to raise awareness of the Prevention Strategy and its aims. **See page 12.**

Through our action, we engaged a total of 75 people

- 56** Participated in the survey
- 9** From the Multiple Sclerosis (MS) Group
- 10** From the Co-production Group

Please note - total figures for quantitative responses in this report reflect the number of survey respondents answering each specific question. Not every respondent engaged with every question. Therefore the totals for each question might not necessarily reflect the figures above.

Demographics

Age range of participants

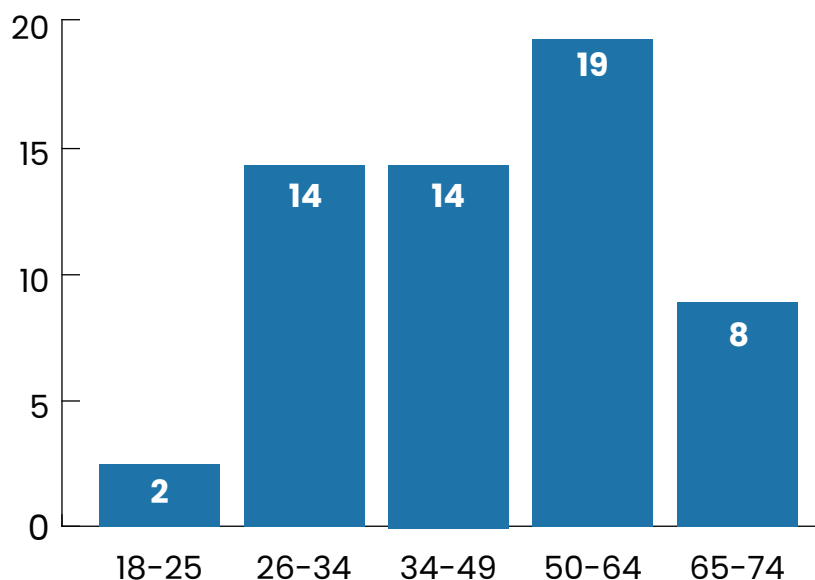


Figure 1: Age ranges for individuals who took part in engagement activity

Gender of participants

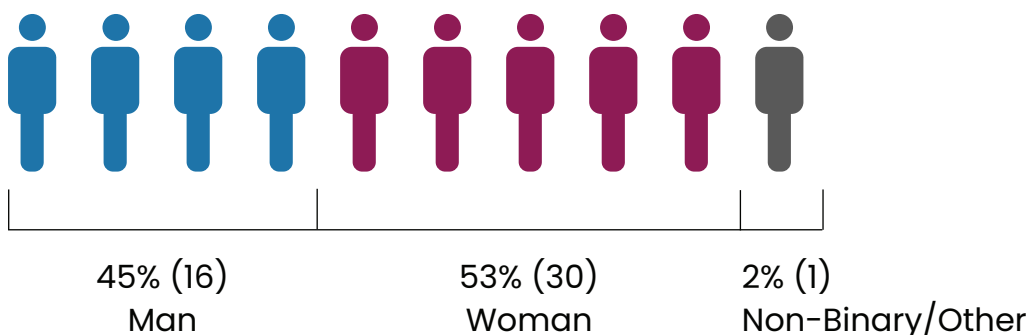


Figure 2: Gender of individuals who took part in engagement activity

Please note - 4 participants did not provide their age or gender

Living status

Of the 43 that reported their living status:

- 18 had their own home with no support
- 20 had their own home with support
- 5 lived in other (e.g. care home)

Project Findings

The following sections summarise the findings across various health-related areas, supported by direct quotes from participants.

These were the takeaways for participants from the public health sessions:

Healthy Eating

Participants acknowledged the importance of a balanced diet, such as including fruit. However, some needed assistance to make healthier food choices.

“Some people feel they can choose for themselves what is healthy food to eat, but others cannot make good decisions regarding healthy eating and need support to make the right choices.”

“Choices need to be explained so people can make good eating decisions.”

Exercise

Participants highlighted that exercise is important, but many require one-to-one support to participate in activities. Without adequate support, some are unable to engage in physical activities.

“Some people are left just to sit and not do any activity as it can become a battle. People may need to be offered an activity that is right for them not just what is the easiest option.”

“People need information at the right level to make a good choice.”

“Are staff trained to have conversations about these things? Are health trainers available across Wiltshire?”

Common activities for staying healthy were acknowledged and included: Walking, going to the gym, cycling, boxing, dancing, using a scooter, treadmill exercises, bowling, athletics, and swimming.

Mental Health and Wellbeing

Participants shared that listening to music and watching sports helped their mental health.

Smear Tests

Participants shared their experiences regarding smear tests and were generally positive. Participants appreciated the professionalism and support from staff, although a few reported discomfort and felt that there had not been adequate explanations.

“Listened to all my questions and provided clear answers.”

“Embarrassing.”

“A bit claustrophobic as it was in a lorry and made to undress waist down and made to sit in a very small room, didn’t know what was happening.”

“Like an express train running over me.”

“Explained what was going to happen and made me feel comfortable and relaxed.”

Overall, participants felt that the experience had improved over the years, though there were still concerns about explaining procedures clearly.

Breast Screening

Participants found breast screening to be uncomfortable, especially when not adequately informed about the procedure. Communication issues were highlighted, particularly when requests were dismissed or not fully understood.

“Radiographer was slightly put out that I wanted one side done before the other although I had a valid reason.”

“It was difficult, and I wasn’t kept informed about what was happening.”

Testicular Cancer Awareness

There is a need for increased awareness around testicular cancer. More information should be made available to encourage regular self-checks and open discussions.

“After going through the prostate session, I repeated the testicle one... since having the talk from Emily and Matt.”

Bowel Screening

Some participants were unaware of their eligibility for bowel screening and found the instructions confusing. The interactive session helped clarify the process using a film and a practical demonstration.

"Had to read the instructions few times to make sense of them."

"Explaining what would happen in advance for example the Bowel Screening Test arrived out of the blue. I didn't know about the test nor that I was suddenly included."

Oral Hygiene

We also spoke to the people from the Medley about oral hygiene and here are some of the quotes that we received.

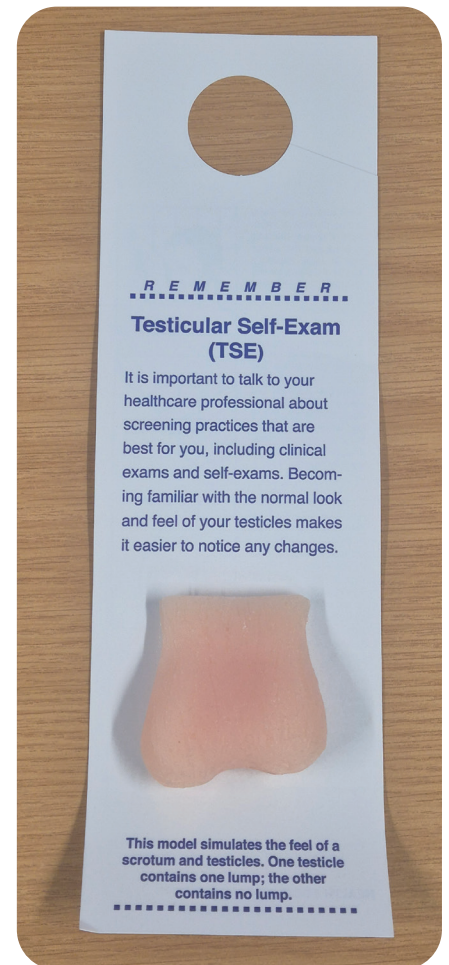
"I brush my teeth twice a day."

"I used the toothpaste. It was good."

"I like healthy eating. I like the taste and it is good for me."

"We got a pack with a toothbrush, a timer, toothpaste and a booklet."

"I've used my timer."



Case Studies

We spoke to three people regarding their experiences on health checks.

Case Study 1 – David*

David told us that he received a letter from his doctor informing him that he was due for his annual health check.

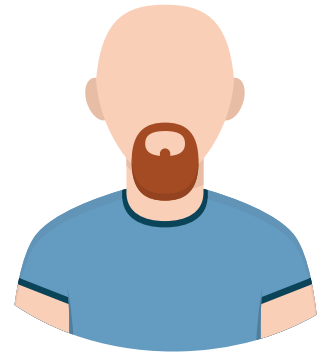
Generally, he said: *“Doctors are good at monitoring my blood pressure.”*

David has been at the same surgery since birth. The majority of the time he goes to the doctors on his own but his mum will go to if he is receiving lots of information as he might forget.

David also said: *“It is hard to get an appointment, the surgery uses a triage system.”*

He likes any information via text, NHS app, letters or email.

David is currently on a Diabetes Prevention Programme, which is a group session of around 20 people. He would rather it was one to one as it's more beneficial to him as he can be apprehensive about asking questions in a group. Sometimes it's embarrassing.



Case Study 2 – Simon*

Simon speaks to his surgery on the phone and face to face. His carer helps with liaison and speaks to them on the phone if any issues. The family carer helps with the liaison.

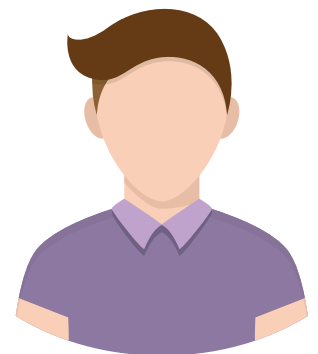
Simon often struggles to get an appointment but he has someone who supports him.

The doctor insisted on a carer attending appointments with Simon, so he felt he had to change his GP. Simon thinks that there is some paperwork missing at the GP.

Simon was in hospital for a couple of weeks due to having a stroke. He fell asleep in the ambulance on the way to the hospital.

Simon felt he was well looked after in hospital and fed well.

When released from hospital he received support from Wiltshire council.



Due to the stroke Simon is unable to drive and will be reassessed in 6 months. He is not doing any heavy manual work, so is doing gardening and housework.

Wiltshire Council and Simon's niece supported him to get out and about initially but now he is using the bus during the week.

Simon has a nurse for support for his diabetic issues, who attends his house.

**Not their real names.*

Case Study 3 – Barnaby



The Voice It, Hear It team has also produced a video case study and the above image is a still from the video. The video case study features Barnaby's story and will be shared as a video file with this report.

Summary of Findings

Recurring Themes

- Staff are generally helpful, but screening experiences can be uncomfortable.
- Participants need support to understand the information provided and what each screening involves.
- Clear, repeated instruction would be beneficial.
- Staff need to be empathetic and understanding of the individuals needs, which generally they are.
- Consistent and clear communication between healthcare providers and patients with learning disabilities is crucial.

Improving Screening Experiences

- Provide clear information on what to expect before and during screenings. i.e. What was going to happen, when it would happen, how it might feel.
- Use easy-read formats and simple language.
- Offer comfortable, sensory-friendly waiting areas.
- Having access to anxiety medication if needed.
- More reminders for screening appointments
- Train health professionals to better understand autism and other disabilities.
- Ensure non-intrusive testing options.

Communication

- Use modern communication methods (e.g., emails, texts, WhatsApp) for appointments and updates.
- Letters should include comprehensive details, such as directions to hospital departments, parking information, and public transport guidance.
- Send reminders via text when letters are dispatched.

Appointments

- Restore the option to make appointments via email, which has been a vital service for those unable to call or visit in person.
- Allow for longer appointment slots and create quieter waiting areas to accommodate specific needs.
- Clearly mark files for individuals with conditions such as autism or learning

disabilities.

- Reception staff need to stop putting up barriers and making people feel that their need for an appointment isn't important.
- Need a system in place to highlight whether someone has a chronic illness, disability, hidden disability or learning disability

General Comments

'Screening is a brilliant idea. However, if you are a man, you are subjected to only two possible screenings. Prostate, heart, and blood pressure screenings are often ignored despite being significant health risks.'

"The Sunflower lanyard has become a big help. I only wear it for medical appointments to remind people of an invisible disability."

"There are not enough tests for men only two available."

Please see recommendations, reflections and proposals on the next page

Recommendations, Reflections and Proposals

Effectiveness of Health Screening Packs

The health screening packs, designed in easy-read formats, have been particularly effective. They were accessible and straightforward, allowing service users to understand and act upon the health information provided. The success of these packs, as observed during this pilot, suggests that expanding their availability could be highly beneficial. Distributing these packs more broadly would empower more individuals with learning disabilities, encouraging them to take responsibility for their health and wellbeing.



The packs have also proven to be a valuable tool for carers. They help explain health practices and screenings to those they care for, promoting a sense of empowerment and autonomy among individuals with learning disabilities. By using these packs, carers can better support service users in understanding and managing their own health, leading to increased control and improved outcomes.

Expansion and Accessibility

Given the positive feedback and practical benefits observed, it is recommended to expand the rollout of these health screening packs to a wider audience. Testing their use with a larger group will provide valuable insights into further refining and enhancing the materials. This will also help reach those who are capable and willing to take responsibility for their own health, enabling them to better understand health information and make informed decisions.

Discussions are underway about the possibility of setting up an online bookcase where these health screening packs can be easily accessed. Such a resource would be invaluable for individuals, their carers, and healthcare professionals, providing a central hub for health information that can be readily shared. Making the packs available online will help ensure consistent and widespread access, regardless of location.

Recommendations for Future Actions

Expand the Health Screening Packs

Roll out the packs to a wider audience beyond the initial pilot, allowing more individuals with learning disabilities to benefit from these accessible resources. Carers could be encouraged to use these packs, as they help explain key health concepts and empower those they support.

Develop an Online Health Resource Hub

Establish an 'online bookcase' where the health screening packs and other resources can be hosted. This could be located on platforms like "Your Care Your Support" and "Wiltshire Together/All Together," making it easily accessible for individuals, carers, and health professionals. The online hub would serve as a one-stop resource for health information, improving ease of access and distribution.



Allocate More Time for Health Sessions

Ensure that adequate time is allocated for individual health sessions. Participants need to feel safe and not rushed, with clear explanations given in straightforward language. This is particularly important for individuals with disabilities, as it allows them to absorb and understand the information better.

Train Healthcare Staff

Provide comprehensive training for healthcare professionals on how to effectively communicate with individuals with learning disabilities. This training should include the use of clear, simple language and techniques for creating a calm and supportive environment during health screenings.

Ensure Accessibility to GPs and Health Visitors

GPs and health visitors should be given easy access to these packs so they can use them to explain health procedures, screenings, and general wellbeing practices to patients. This will enhance the overall healthcare experience and ensure that individuals with learning disabilities receive the information they need in a way that is understandable and actionable.

Create Short, Accessible Videos

Develop a series of short, accessible videos with clear transcripts. These videos would offer straightforward explanations of health procedures and screenings, helping individuals with learning disabilities to better understand what to expect. Making these videos available on the proposed online bookcase would further enhance accessibility, ensuring that individuals, carers, and healthcare professionals can easily share and access these resources.



Appendix 1: Survey Results

Type	Question	Yes	No	Mixed*	Unsure N/A**
Appointment Letters	Easy to understand?	11	4	1	0
	Information sufficient?	10	4	2	0
	Additional information accessible?	4	6	0	4
	Preferred appointment booking method	5	0	8	3
Testicular Check	Shown how to check?	2	4	0	7
	Confident in checking?	1	1	2	7
	Who to talk to if concerned?	3	0	0	7
Breast Check	Shown how to check?	7	5	0	3
	Confident in checking?	4	0	3	0
	Who to talk to if concerned?	7	0	0	3
Smear Test	Information provided?	6	2	0	0
	Questions answered?	6	1	0	1
Bowel Screening	Information provided?	5	1	0	0
	Instructions clear?	4	1	0	0
	Kit easy to use?	5	0	0	0

* Mixed refers to responses which included 'sometimes/a bit/somewhat'

** Refers to responses which indicated 'don't know/N/A/Other'

Acknowledgements

Our thanks to the individuals who gave their time to take part in this engagement activity, your valuable input will help to inform this important work. Thanks also to Wiltshire Council for listening to the voices of service users to help make local services better for everyone.

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