

Access to screening for people with learning disabilities

April 2018



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Introduction

In January 2018 Healthwatch Solihull attended a meeting with the Learning Disability Partnership Board to discuss carrying out a joint project as part of their ongoing work advocating for the rights of adults with learning disabilities.

The board identified healthcare access and inequality for adults with profound learning disabilities as their big issue for 2018. They hoped to design a project identifying physical and attitudinal barriers to health care access, to produce a set of recommendations for practitioners and commissioners. They were particularly interested in whether adults with learning disabilities were being invited to regular screening appointments and their Annual Health Check. They hoped to determine whether they attended and how they were treated by staff during their appointments. If people were not attending these appointments, what were the physical and attitude barriers that stood in their way? In addition people with learning disabilities are entitled to an annual health check, and the board were eager to see whether people were being invited and whether they attended.

Background

Following a Formal Investigation in 2006 the Disability Rights Commission recommended the introduction of Annual Health Checks for people with learning disabilities in primary health care services in England as a reasonable adjustment to address the health inequalities they faced.

The Department of Health responded with a commitment to introduce 'regular, comprehensive health checks for people with learning disabilities'. This was based on their conclusion that this was 'the best way to improve the health of people with learning disabilities'. (Department of Health, 2007).

A robust body of evidence suggests that providing health checks for people with learning disabilities in primary care settings is effective in identifying previously unrecognised morbidity, including morbidity associated with life-threatening illnesses. (Robertson, Roberts, Emerson, Turner, & Greig, 2011)²

In 2014-15 the number of eligible people who received their Annual Health Check was 43.2%¹. Coverage improved with age. In 2014-15:

- fewer than 10% of 0-9-year olds received their annual health check;
- fewer than 20% of 0-17-year olds;
- around 40% of 18-34-year olds;
- over 50% of people aged over 45.

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Statistics show that individuals with learning disabilities have a lower life expectancy than the general population¹. In 2014-15 the disparity for women was 18 years, and for men it was 14 years¹.

For cancer screening and access a recent cohort study looking at access to cancer screening by people with learning disabilities in the UK concluded that despite recent initiatives, people with learning disabilities are still significantly **less likely** to receive cancer screening tests than those without learning disabilities (Osborn et al, 2012)³.

Rates of screening for colorectal, cervical and breast cancer were all found to be **lower** for people with learning disabilities than the general population¹.

It has been well documented over a number of years that women with learning disabilities have a much **lower** participation rate in cervical and breast screening programmes than women in the general population (Biswas et al, 2005; Osborn et al, 2012; Reynolds et al, 2008)³.

Some of the barriers people have examined are:

- Practical barriers - such as lack of routine use of “easy to read” invitations, difficulties using appointment systems and mobility issues.
- Communication barriers – identified by healthcare professionals as one of the most significant barriers to breast cancer screening (McIlfatrick et al, 2010).
- Attitudes and knowledge of professionals, support services and family carers e.g. women with learning disabilities are more likely to be ‘ceased’ from cervical or breast screening programmes than women without learning disabilities (Reynolds et al, 2008).
- Attitudes and knowledge of people with learning disabilities – people may not understand the importance of screening and feelings of fear and anxiety can be a barrier to participation.
- Consent issues - concerns about the capacity of people with learning disabilities to consent to participate in screening programmes can also be a barrier (Mc Ilfatrick et al, 2011). 3

Aims

¹ Health and Care of People with Learning Disabilities: England 2014-15, NHS Digital, 2016

² Emerson et al (2012). Health inequalities and People with Learning Disabilities in the UK:2012. Improving Health and Lives Learning Disabilities Public Health Observatory. ³ Hatton et al (2011). Reasonable Adjustments for People with Learning Disabilities in England. A national survey of NHS Trusts. Improving Health and Lives Learning Disabilities Public Health Observatory. ⁴ Turner et al (2012). Making Reasonable Adjustments to Cancer Screening. Improving Health and Lives Learning Disabilities Public Health Observatory.

Access to Screening and health checks for people with learning disabilities 2018

- To carry out qualitative research and learn about the experience of health checks and screening for adults with profound learning disabilities.
- To produce a set of recommendations for making these services more accessible

Methodology

It was important to board members that the research carried out would reflect the unique experience of each patient and allow their voices to be heard. They wanted the research to have a high level of validity in order to produce a set of recommendations that could be used to bring about change and improve equality of access. For these reasons we decided that focus groups would be the most effective way of gathering information.

We carried out desk research into the types of screening offered by the NHS, frequency, eligibility and criteria and determined that carrying out separate focus groups with men and women would possibly enable people to speak more freely and more comfortably discuss their experiences. We worked with the board members to identify organisations who could assist us in facilitating focus groups during their usual meeting times. The board were keen that the focus group venues needed to be accessible and that the timings of events should be chosen to allow the maximum number of people to attend, so we felt that combining focus groups with existing sessions would address both needs.

To make the focus groups as accessible as possible an “easy read” guide was developed to accompany the discussion with pictures illustrating the types of screening and health checks that people might have been offered. We also produced a focus group information sheet in both plain text and “easy read” so that recipients could gain as much information as possible during the sessions and have documents to take home to their parents/carers if applicable.

We carried out 3 focus groups speaking to 14 females and 12 males, their carers and support workers. All materials used can be found in the appendices’ and the findings are discussed below:

Findings

Finding information and keeping well

We asked groups how they would go about accessing information on how to keep healthy. A general discussion took place and the responses we received were mixed. People used their computer at home to actively search online. Some people said the TV was helpful for accessing information and some people received information from their doctors although when this comment was made, several people disagreed that this was a suitable option.

From past experiences people had found information they had received from SoLO to be useful and they had received specific health information sessions from SoLO regarding healthy eating. Within the same organisation they had also completed a “biology session” to highlight parts of the body and what could go wrong/ make them unwell which they found useful.

A parent in the group explained that her daughter relied on her (mum) for all her health needs.

Annual health checks

There was a mixed response from the groups regarding annual health checks. When we asked one group if they were called for an annual health check there was no response and the support worker in the group said that they were called sometimes monthly or annually. The support worker informed us that they would receive a written postal invitation.

One person in this group did emphasise that he did go for a heart check, but he was unsure if this was part of the health check. The lack of response may indicate that people are either not invited don't attend or when they do attend may not realise they are there to receive a health check. Within the other two groups there were some general discussions about annual health checks and some people reported that they had been invited for annual health checks and some had recently attended. One person said "They told me my weight is alright, I just need to eat more fruit and less chocolate."

There was also a mixed response of how people received their results from annual health checks and the effectiveness of this communication. One person received her results at the actual appointment and she found this useful. Another received their results via email and reported no problem with that. One parent explained that she rang the surgery for her daughter's results as her results were given over the telephone. She said that her daughter would be unable to do this for herself as she is nonverbal and there is a note on the system that mom is the first point of contact for her results.

Another carer added that for screening results you are expected to ring the surgery. She felt that several young adults with learning disabilities would struggle with this. Similarly, one individual had his sister down as point of contact and the surgery would send his results to her which in turn meant that he then had to contact his sister for her to update him on his results. The group had a positive discussion around the use of Makaton/PECS and it was discussed that this is a good way of communicating results to individuals. One mother explained that a letter in Makaton is sent to her daughter with a plain text version attached to the back for her. It was not clear if this was done automatically but mom explained that she had requested this service from the Practice. The support worker added that in supported living, letters go directly to the individual and support workers help assist with these matters and that sometimes the GP rang the centre themselves.

A discussion was held around access for deaf and hard of hearing patients. It was said that deaf and hard of hearing people cannot access the same services in GPs and hospitals as there are no interpreters. It was reported that some doctors write down what they need to communicate and in turn the patient writes a reply. It was said that this may not be an effective way of communicating and that this in itself may just add to the barrier i.e. some people have additional needs with reading and writing and may therefore find this difficult.

In two of the groups most of the people knew about or had attended a physical health check and one mother reported that she knew people that have never been invited for health checks. It was

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not known though why this was the case. Was it due to people not being identified as having a learning disability, inappropriate ways of communicating or a lack of awareness of health checks?

There was a mixed response in people understanding if they were attending health checks when people had attended an appointment. Some understood what was happening and understood when the doctor explained something to them. For example, some people knew that they had heart checks and others spoke about blood tests stating “They talk to me about my blood tests ... yes he goes through it and I understand”

Some of the statements below highlight the mixed understanding of the purpose of health checks:

“I don’t understand what they do, they listen to my pulse”.

“I go to the doctors with my mom. Don’t go by myself, doctors usually ask mom. I don’t take much interest in my own health. I let mother worry about my health”.

“...he (the doctor) never explains”.

What would make going to the doctor easier?

In one group 5 people disliked going to the doctors and 3 people liked going to the doctors and 1 person stayed neutral. In another group it was the opposite, 5 people said they liked going to the doctors, 1 didn’t mind and 1 didn’t like it. In more detail people reported that they felt embarrassed going to the doctors and one said that they didn’t like having to sit and wait in the surgery. Most agreed that they went with their mothers and that this made it easier for them. One mom said, “As long as I am with her she’s fine.” It became apparent that most of the people in the group relied on another person to take them to their appointment and that this impacted on appointment attendance. One person said “Getting there is an issue, I used to go with mom but now she works full time now and I can’t get there “.

People reported that it was sometimes hard to get an appointment with their GP and one person explained that they used the Walk-in Centre, and this was the easiest way to get an appointment. There was a discussion about familiarity in terms of how to make appointments more manageable. A mother said that she often accompanied her daughter to appointments (especially screening appointments) so that her daughter was familiar with the procedures first.

People said that they felt they should be allowed more time with their GP to better explain and understand what they were being told. It was felt that doctors need to be more sympathetic to the needs of individuals. For example, if a person with learning disabilities does not reply to a screening letter more should be done to follow it up and encourage participation. There should be a named contact of someone who is responsible for their health. One of the patients in the group had a document within her GP practice that showed what she “did and didn’t like” and how to communicate with her. It was stated that there also needs to be a better transition from living with parents to supported living.

Screening

In one group people were not aware of what screening meant and therefore were unable to answer if they had been called to any screening services. The support worker in the group stated that they felt that individuals would not know what screening was and that in supported living letters would be sent and that support workers would deal with it and would help with booking appointments.

When we addressed one of the women's' group about screening a mother said that her daughter hadn't been for a mammogram but that her daughter had been for a cervical smear. Her daughter "did not like this" and she had decided that her daughter would not attend again.

In terms of making decisions about screening it was said that it is down to parents making decisions for them. One parent said that it had been agreed with her and the GP that her daughter would not have to have cervical screening.

The anxiety of doctor's appointments was discussed, and it was said that the anxiety for the patient can be so great that it can lead to a panic attack. Due to the anxiety one parent reported that they now had blood tests taken at home via their GP.

As with screening a generic letter with a leaflet was sent when calling the patients in for screening test. Parents and patients both agreed said that it could be improved with a more accessible leaflet containing easy read pictures so as to help understanding.

A parent explained that her daughter initially refuses to go for screening tests and she has to persuade her to go. It was stated that it may be a good idea if they could see an educational video of what to expect. The group were unsure if this information is given in schools or other service providers before they reach the appropriate screening age. They questioned whether Solo could provide this facility. Parents all felt that an educational video may help to reduce anxiety and nervousness before and during the appointments.

Parents discussed whether the age for screening for people with learning disabilities should be lowered and that testicular testing should be included as part of routine screening. They felt that people needed to understand how to check themselves and what to do if they find something. Again, this information should be provided in an easy read/ accessible document.

It was also mentioned that some people who request smear tests were unable to gain access to the surgery they required and further exploration may need to be given to understanding what this barrier to services was.

Dignity and respect

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8 people reported that they felt like they were treated with dignity and respect. A mother reported that her daughter was non-verbal and that her GP always addressed her daughter directly. Some people reported that their doctor was “nice” and did explain why they were there.

But some people also felt that the doctor didn’t speak to them directly.

“The doctor speaks to my mom and dad”.

“I wish the doctor would speak to me”.

“My doctor just looks at me like he thinks what the hell”.

“My doctor is grumpy”.

3 people agreed that doctors spoke too fast and one mother reported that she felt that she and the doctor had to try and guess her daughter’s illness when she is poorly and visits the GP.

Recommendations

Person centred approach

The focus groups clearly highlighted that everybody requires an individual person-centred approach when accessing health care and screening. Everyone has their own individual needs, and this should be reflected in how the practitioner communicates with their patients, especially in one to one settings. More needs to be done to understand how people want to be communicated with, some people in the group relied on another person to communicate for them and others wished the GP would speak directly to them; clearly ways of communicating effectively need to be established between the GP, the Practice and the patient.

Additional support

Groups highlighted that a large proportion of individuals relied on another person, usually their mother to take them to their appointments. One person stated that they were unable to attend appointments since their parent had gone back to work full-time. It was felt that there may be a gap in support for people with learning disabilities. (Those who are not in supported living rely on family members may not have easy access if they rely on another care giver to attend appointments and also what about those that do not have any support)?

The location and setting of where health checks are offered may be something that needs to be considered e.g. a parent felt that home visits were a great way of controlling her daughter’s anxiety about attending appointments. If a person has no support network and has learning disabilities what steps are made to assist these people? What additional support is there via community services or what steps to assist patients to GP surgeries make? If patients are listed as having a learning disability are they offered home visits, is there transport support?

A call for a greater understanding of Health Checks

There may be a need for some people with learning disabilities to have a better understanding of their own health and to have a better understanding of screening tests that may be made available to them.

In terms of Annual Health Checks, it was unclear that everyone knew the full details of what this involved. This lack of understanding of what actually takes place at a health check was of particular interest for this report as in order to make a positive impact on a person's health and wellbeing it is not clear of the current effectiveness of health checks. Some people had no clear understanding of why health checks were being carried out, what would happen during them and how they would make changes to their lifestyles. For example, if people are told they need to reduce their calorie intake how is this successfully communicated and what support is given to help that person make changes and monitor the success?

In one group there was no understanding of what screening was and this was further confirmed by their support worker. More information needs to be readily available and this information needs to reflect the needs of the individual, whether this be in Makaton or easy read format.

Better communication

Evidence from the study would suggest that individuals often need support to help them understand what is required of them and that when communicating information, it would be helpful to use visual aids, whether easy read documents and or Makaton.

There is a need for patients to be able to express their feelings to their doctor and equally for them to receive information back regarding their health. It is not clear how effectively this happens. There is the need to examine what further aids can be used to help the individual communicate with their GP e.g. anatomical diagrams and pictures to identify how the patient is feeling.

Earlier and more scope for screening

It is worth noting that parents felt that more screening should be available to individuals with learning disabilities. Also, that educational information in easy read be available to help people understand what to look for and what to do if they found something they were not sure about. It was felt that this should be done at a younger age in preparation for screening and this would help reduce anxieties around attending screening appointments.

Earlier education to reduce anxiety

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People thought that more information and discussions in schools would increase the understanding of screening which would help reduce anxiety. An understanding of the reasons for the appointment would make it easier to persuade the patient to attend.

More accessible appointments

It is felt that patients with learning disabilities should receive longer appointments with their GP and that GPs should speak to them directly and not just their parent or carer. GPs should use communication methods appropriate to the individual patient e.g., use of visual aids and Makaton.

Additional resources

Additional arrangements should be made for deaf and hard of hearing people with access to an interpreter for appointments. This is essential to understanding a person's individual needs. It is recommended that personal information included a plan of what the individual requires in terms of communication, how the individual wishes to communicate in and after appointments and if there is a support worker or carer that has authority to assist the individual. Also, as some people had not attended health check appointments it is recommended that more effort be made when invitations are sent out to the person e.g. what is the best way to invite the individual and what is the best way to remind the individual of their appointment? Equally if a person misses an appointment it is important that the surgery knows that this person has a learning disability so that the surgery can be more accommodating when rearranging.

Up to date GP records

There was some evidence that people may not be getting called for their annual health checks. We feel there may be a need to look at patient information to check if patients are registered as having a learning disability and to make sure that there is an effective way of communicating with patients and that more is done to encourage and remind patients to attend their appointments if there are additional barriers to accessing services.

Appendices

Information Sheet

Access to Healthcare: Screening Appointments and Annual Health Check

Healthwatch Solihull and the local Learning Disability Partnership Board are carrying out a joint project looking at healthcare access and inequality for adults with learning disabilities. The focus of this project is annual health checks and screening appointments. We hope to learn whether people are invited and attend their appointments, and how they are treated by staff during these appointments. If people are not attending these appointments, we hope to determine the physical and attitude barriers that stood in their way. Using the experiences that people share with us during these sessions, we will produce a set of recommendations for practitioners and commissioners to make these appointments more accessible.

Your feedback will be shared with Healthwatch Solihull and the Learning Disability Partnership Board. Everything that you share with us, along with everyone else's responses, will contribute towards a written report. While we may talk about aspects of your experience, you will not be identified in any reports, presentation or papers arising from the project. In sharing your views, any information that we collect about you in connection with this interview will remain confidential and will be disclosed only with your permission. You have the right to withdraw your comments at any time and do not have to give any reason for withdrawing.

Your feedback is very valuable, and we thank you for taking part in our focus group.

If you have any further enquiries, please get in touch using the contact details below.

Researcher Contact Details:

Name (Position)

Telephone Number:

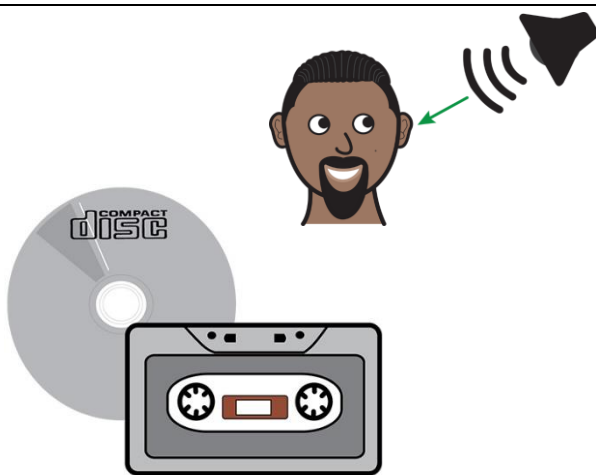
Email:

Name (Position)

Telephone Number:

Email:

AUDIO RECORDING



Do you consent to the audio recording of the interview for transcribing purposes? (This will not impact on your ability to participate in the research)

☐ Yes, you may audio recorded my voice

☐ No, I do not want to be audio recorded

PARTICIPATION

I understand that my participation in this research is voluntary

I understand that my participation in this research is confidential

I understand that my participation in this research is anonymous

I understand that I can withdraw my responses from this research at any time without explanation

Signature:

Printed Name:

Date:

Learning Disability Partnership Board Focus Group Template

Before Starting

- Ensure the room is conducive to promoting discussions.
- Make sure you (the facilitator) set the tone for discussions and put the group at ease
- Ensure that every participant is given a chance to air their opinions (including the quiet ones)
- Make sure you monitor time closely and allocate enough time to each question.
- Inform people that they have a right to leave the group at any time
- Set ground rules: switch mobile phones off, everything will remain confidential, only one person to speak at a time, there is no right or wrong answers etc.
- Ask if the group are happy to have the group recorded audibly for the purposes of the write up only
- Capture all observations including non-verbal body language and morale

1. Introduction (spend no more than 5 minutes on this activity)

Welcome the group

- Thank them for attending
- Invite them to sit wherever they wish
- Remember the points above

Introduce the purpose and context of the focus group

- Explain who you are
- Explain how the project came about
- Explain the format and duration of the focus group session
- Explain how the information will be fed back to ECS

Explain how the information will be recorded

- Inform them that a note taker will be recording the information
- Inform them that no names will be recorded or comments attributed to any individuals
- Explain how information will be analysed and used

Make introductions

- Introduce yourself and any co-facilitator
- Ask group to introduce themselves
- Ask if anyone has any questions before you start

(Record questions and observations here)

2. Ice breaker (spend no more than 5 minutes on this section)

- “What makes a good trip to the doctor’s?”
- “What do you remember/what sticks in your mind about the last time you visited the doctors?”
- “Describe _____ in one word”
- “Would anyone like to share an experience about...”
- “What has been your most positive experience of _____?”

<p>3. Have you been offered the screening appointments available to you, and did you attend?</p> <p> <input type="radio"/> Were you sent a letter inviting you to a screening appointment (see below)? <input type="radio"/> Did you attend? If no, why not? <input type="radio"/> What would make it easier for you to attend? </p>
<p>Women:</p> <ul style="list-style-type: none"> • Cervical smear (age 25-49) every 3 years • Mammogram (age 50-70) every 3 years <p>Men:</p> <ul style="list-style-type: none"> • Abdominal aortic aneurysm (aged over 65) one off <p>All:</p> <ul style="list-style-type: none"> • Bowel cancer scope (age 55) one off • Bowel cancer faecal occult blood test (age 60-74) every 2 years <p>Diabetes:</p> <ul style="list-style-type: none"> • Diabetic eye screening (over aged 12) once a year <p>(Prostate screening is not routinely offered.)</p>

4. Are you offered your Annual Healthcare Check, and did you attend?

- How were you contacted?
- What was offered to you once there?
- When did you last attend?
- Does anything stop you attending? What would help you to go?

The annual healthcare check should include:

Weight; heart rate; blood pressure; blood and urine tests; behaviour, lifestyle and mental health; epilepsy check; review prescription medicines; check chronic conditions; review of links with other healthcare professionals.

5. During your appointment, were you treated with dignity and respect?

- ☐ Did you understand what was happening and why you were there?
- ☐ Did you have a carers or assistant present?
- ☐ If no, what could have been done better?

6. How are your results communicated to you by the doctor?

- ☐ Were you sent a letter?
- ☐ Is a carer or family member able to access your information through the GP/clinic?
- ☐ If you required any follow up care, was this clearly communicated?

7. Any other comments? How could your experience have been improved?

8. Focus group close. Thank everyone for sharing their experience, and let them know when to expect as report/news on the outcome.

Name of group:

Number of participants:

Facilitator(s):

Date:

Type of screening	Related condition	Eligibility	Frequency
Mammogram	Breast cancer	Women aged 50-70	Every 3 years
Eye screening	Diabetes	Diabetic people over age 12	Once a year
Cervical smear	Cervical cancer	Women aged 25-49	Every 3 years
		Women aged 50-64	Every 5 years
		Women over 65	If not screened since age 50, or if they have had abnormal tests in the past
Faecal occult blood (FOB) test	Bowel cancer	People aged 60-74	Every 2 years
Bowel scope screening	Bowel cancer	People aged 55	One off
Abdominal aortic aneurysm (AAA) screening	Abdominal aortic aneurysm	Men over age 65	One off
Annual Health Check <ul style="list-style-type: none"> • Weight • Heart rate • BP • Bloods and urine • Behaviour, lifestyle and MH • Epilepsy • Review prescription medicines • Check chronic conditions 	Learning disability	People over age 14 who have been assessed as having a moderate, severe or profound learning disability	Yearly


<ul style="list-style-type: none"> Review of links with other healthcare professionals 			
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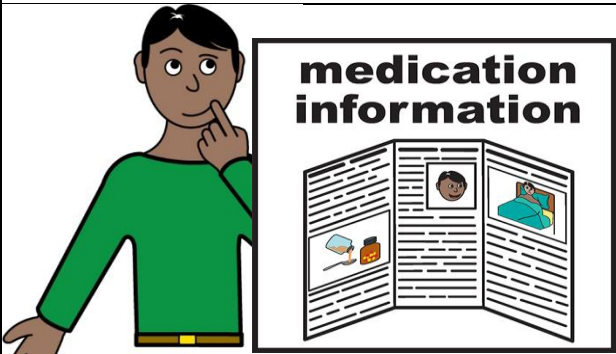
All of the above screens and checks rely on the patient being registered at a GP surgery.

There is no routine prostate screening programme for men in the UK, as the benefits have not been proven to outweigh the risks. However, men over 50 can request a free prostate specific antigen (PSA) test on the NHS.


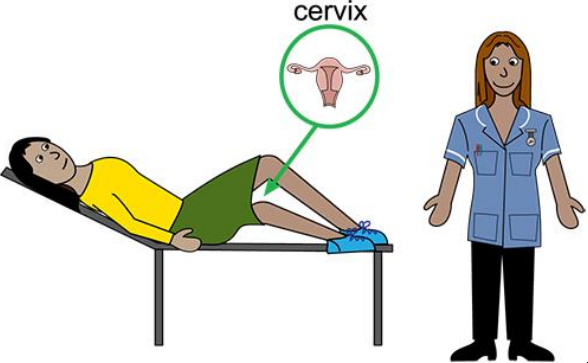
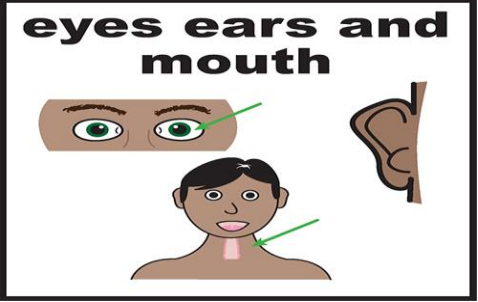
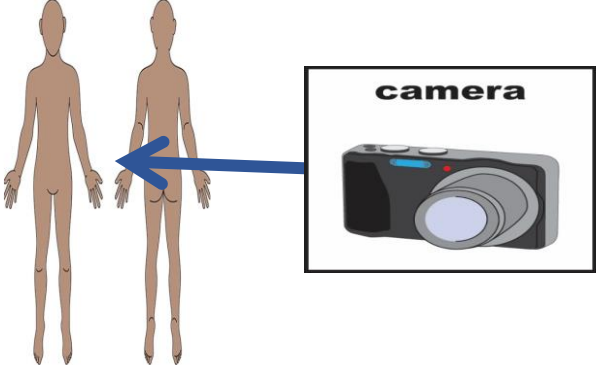
Access to Healthcare Discussion pack

Screening Appointments and Annual Health Check

1		<p>Welcome Introduce ourselves Speak one at a time</p>
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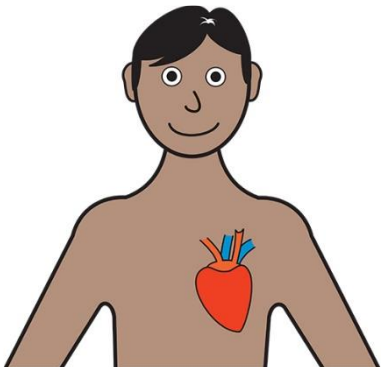
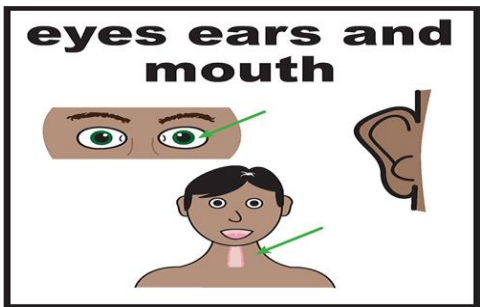
2		<p>Explain the project</p> <p>Access to healthcare</p> <p>How to make it better</p> <p>Any questions?</p>
3		<p>Ice breaker</p> <p>Where can you get information about keeping yourself healthy?</p>

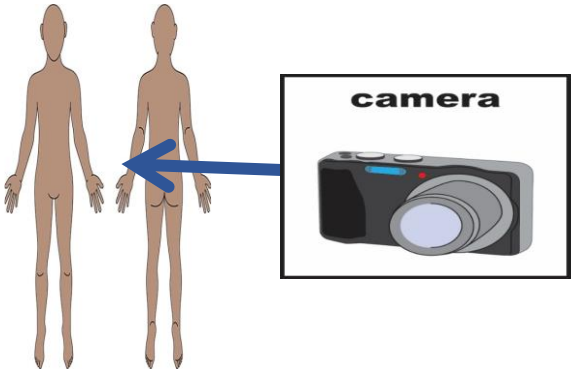

For Women

4		<p>Breast Screening Mammogram Age 50-70 Every 3 years</p>
5		<p>Cervical Smear Test Age 25-49 Every 3 years</p>
6		<p>Diabetic Eye Screen Over 12 years old Once a year</p>
7		<p>Bowel Cancer Age 55 Using a camera Only once</p>

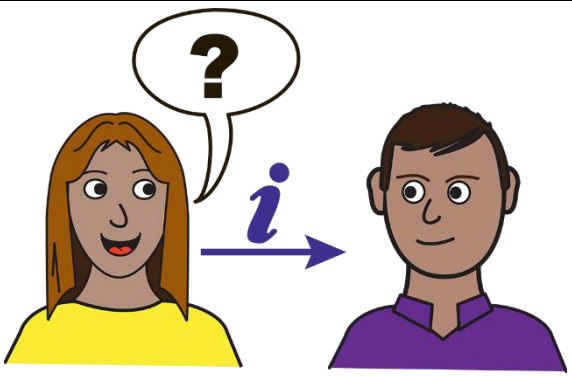
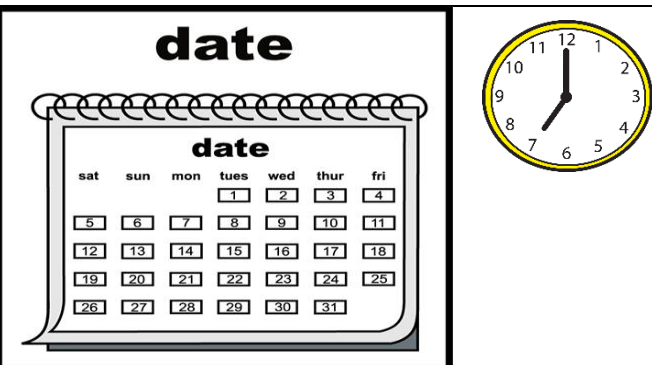
8		<p>Bowel Cancer Age 60-74 Test at home Once a year</p>
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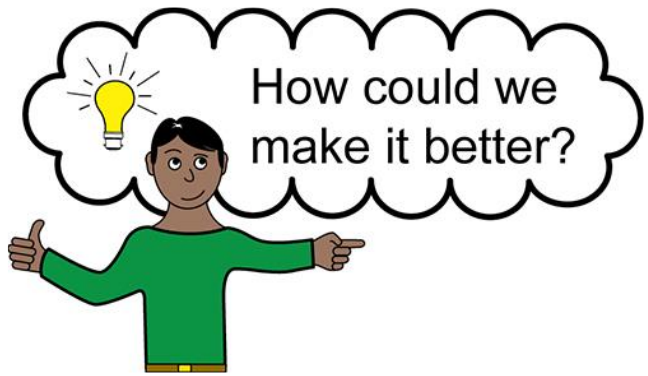
For Men

4		<p>Healthy Heart Ultrasound on the stomach Aged 65</p>
5	<p>eyes ears and mouth</p> 	<p>Diabetic Eye Screen Over 12 years old Once a year</p>


6		<p>Bowel Cancer Age 55 Using a camera Only once</p>
7		<p>Bowel Cancer Age 60-74 Test at home Once a year</p>

Annual Health Check

9		<p>Information Where can you find information?</p>
10		<p>Attending When did you last go?</p>

11	 <p>health check</p>	<p>Your Health</p> <p>Weight</p> <p>Healthy heart</p> <p>Blood test</p> <p>Urine test</p> <p>Lifestyle</p> <p>Epilepsy</p> <p>Medicine</p>
12	 <p>How could we make it better?</p>	<p>Making it better?</p>

Your Appointment


13		<p>Respect and Dignity</p> <p>Private</p> <p>Understanding</p> <p>Helpful</p>
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		Making it better?
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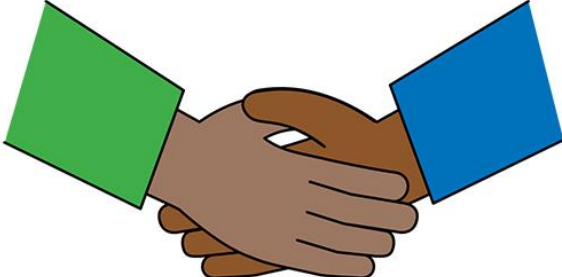
Getting Your Results

14		Contacting you Phone, letter, online?
15		Support Who can help you?

Any other thoughts?

16	<p>share ideas</p> 	<p>What do you think?</p> <p>How can we make it easier for you to stay healthy?</p>
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Thankyou

17		<p>Thank you all for your help!</p>
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Thanks to  easy on the  for the use of their image bank © LYPFT
www.easyonthei.nhs.uk

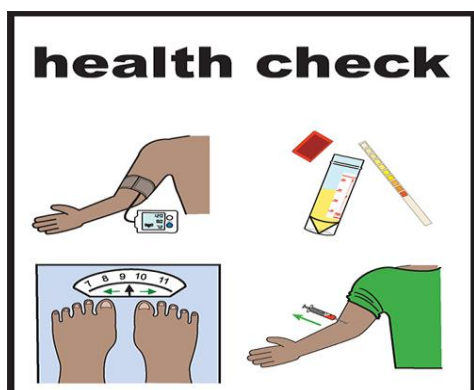
Information Sheet

Access to Healthcare

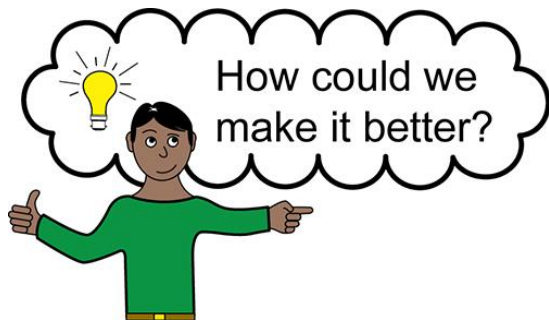
Screening Appointments and Annual Health Check

The Learning Disability Partnership Board and Healthwatch Solihull are working together on a project

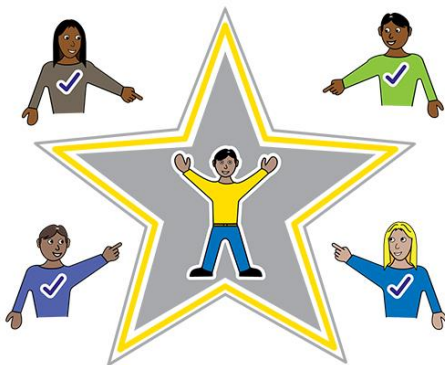
We want to see whether you are invited for annual health checks, and other screening appointments. These can help to keep people healthy.



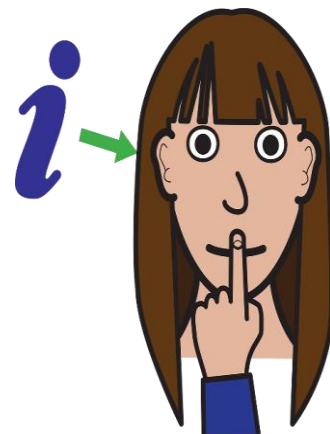
We want to learn how to make these appointments better for you, so that we can advise health care staff.



By learning about your experiences, we can help people in the future.



Your identity will be kept private, but we will use the information you tell us in a report.



Transcription

Access to Screening and Annual Health Checks

Date	06/02/17
Number of participants	7
Group code	M1
Facilitators	SB and RG

The group seem happy to participate, glad that the girls have been asked to leave/gone for a walk. Scott introduces us and the project, and lets the participants know that although we will use the experiences they share to create a report in order to make things better in the future. In addition to the 7 men, 1 mother and 1 PA sat in on the group, along with 2 SoLO staff.

Icebreaker: How do you get information about staying healthy?

- The doctor [2 others agree, 1 disagrees].
- Internet [1 person disagrees].
- If you're poorly in the hospital, you can get information.
- We got tips from SoLO about healthy eating yesterday.
- We did a biology session, drawing out a body and sticking on the organs, and saying what could go wrong with them.

Annual Health Checks

- No.
- Yes I have one, every year.
- They call you in on the computer. Get a blood pressure test, height, weight, ears, diabetes check.
- SoLO staff had taken one man to a blood test, when he had suffered with gout.
- I don't have blood drawn but did have a blood pressure test.
- You get a scan on your head if you are poorly. I have fits.
- I had an x-ray on my ankle.
- I have a scan on my brain.

How do the doctors contact you?

Access to Screening and health checks for people with learning disabilities 2018

- Telephone or writing.
- That is the best way.
- Heart check – listen to your heart beat. [Several of the men present made the sound of a heart beating, definitely seem to understand what the stethoscope is for].
- They talk to me about my blood test. Yes, he goes through it and I understand.
- I don't understand what they do. They listen to my pulse.
- [Several men in the group agree they have had a blood pressure check with the tight arm band].
- I go to the doctors with my mum occasionally. Don't go by myself, doctor usually asks mum. I don't take much interest in my own health.
- I go with my mum.
- Mum goes with me.
- Mum or care worker go with me. I live independently. Doctor writes to me and I like it this way.
- I go with mum, they check my heart rate.
- Head, ears, blood pressure, blood test.
- Blood pressure machine hurts – goes very tight. Don't know what it is for.
- [SB explains what the BP machine is for].
- He {the doctor} never explains.
- I have a thing on my finger [oxygen monitor].
- My dad takes me to the hospital, not an ambulance. [Staff member says: you often dislocate your joints, the ambulance would probably come if dad was busy at work.]
- We learned about not drinking alcohol at SoLO.
- [PA asks]: Why is testicular cancer not on your sheets?
- [RG explains]: It is not routinely screened by the NHS.
- [PA answers]: Testicular cancer should be included as standard. They need to know how to check themselves and what to do if they notice something. There should be accessible information to help them check and understand. They should be screened or it should be

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added to the AHC, we know several people who have suffered, and they were young (20's/30's).

- I let mum worry about my health.
- [Mum says]: we know people who have never been invited for AHC's.

Do you like going to the doctors?

- 5 people said they like going to the doctors
- 1 doesn't mind.
- 1 does not like it.
- I feel like I've been listened to.
- I don't like the mouth swab, it makes me gag.
- I don't like the thing on your chest [stethoscope] its cold.
- I have a sore tongue, the doctor looks in my mouth.
- [MUM]: What about prostate?
- [RG explains it is available on request through the NHS]
- Prostate checking should be included. For this and testicular, you need a leaflet about changes.

What would be the best way to give info about testicular/prostate cancer?

- Do parents/PA's have the request those tests? Should we be asking the doctor?
- We need to know how to teach them to check and watch out for bowel, testicular and prostate issues.
- There should be pictures to make it easy for them to know what to look for, and when they need to tell someone.

Focus group close.

Access to Screening and health checks for people with learning disabilities 2018

Access to Screening and Annual Health Checks

Date	06/02/17
Number of participants	7
Group code	W1
Facilitators	EC and RG

Present in the group were 7 young women with learning disabilities, two parents and two support staff. Emma introduced us, Healthwatch, and the nature of the project. She also explained that the women's identities would be kept anonymous, but their views would contribute to a report.

Icebreaker: Where can you find information about how to keep fit and healthy?

- On the computer/laptop that I use at home, I can search online.
- I watch the telly.
- She depends on me [her mum] to sort out appointments and everything.
- She hasn't been for a breast screening, wouldn't stand that. She had a smear test once but would never do it again, as she did not like it.
- It comes down to the parents making decisions for them.
- The panic and anxiety can be so great that it may lead to a panic attack at the idea of the doctors. We have a home doctor who comes to the house and does blood tests and other things, or we go to the walk-in centre. We do not go to the hospital.
- It's just hard to get an appointment, especially at Haslucks Green.
- [Others agree] Even if you ring up on the morning you can't get an appointment on the day.
- [For one woman] It's been agreed with her, her mother and the doctor that she doesn't have to have the screening anymore.
- Get sent the screening call-up by letter.

How could we make going to the doctor easier for you?

- Going with mum
- [Mum said:] "As long as I'm with her she's fine".
- Getting there is an issue – used to go with mum but now she works full time I can't get there.

Access to Screening and health checks for people with learning disabilities 2018

- Most agree that they are taken by their mum.
- 1 woman said she likes the blood test.
- [Mum says:] Mums have to guess what's wrong, if they're poorly we have to guess and so does the doctor.

Annual Health Checks

- 2 people said yes they have been invited for an AHC.
- One went yesterday: "My weight is alright, I need to eat more fruit and less chocolate".
- Get results by email after AHC and find that to be alright.
- We talk about the results in the appointment, and find that to be okay.
- [Mum said about her daughter:] She goes every year, they check her for diabetes and other things. I phone up afterwards to get her results – as she would not be able to do this. I am a listed contact for her results.
- One lady gets letters sent and addressed to her in Makaton/PECs. For example, if her results showed she was overweight they would have a picture of a fat belly with the symbol for "less".
- [Others agree that this could be useful].
- You have to request this service from the doctors, she is with Oliver Healthcare, but both Oliver and the GP produce these Makaton letters.
- A copy in Makaton is sent, with a plain text copy stapled to the back for mum.
- Often for screening you are expected to ring for results, which a lot of our young adults can't do.
- Getting to an appointment is an issue.

Dignity and respect

- 3 people say yes, they do feel like they are listened to and respected.
- [Mum said about her daughter]: they speak and address questions to her, not me [although she is non-verbal most of the time].
- My doctor is nice.
- They explain why you're there.

Access to Screening and health checks for people with learning disabilities 2018

- Can always take a parent or carer with you.
- I can't take my dad.
- In some appointments, if you are registered learning disabled with the GP, they can give you longer appointments.
- Health check appointments are also given more time.

How can we make things better?

- Easier access would be the main thing.
- You need to know you're going to be ill 2 weeks in advance.
- We really struggle to get appointments – it's always been the case.
- We use the walk-in/badger clinic now as you can wait and actually be seen by a doctor that day.
- [Mum said about her daughter]: She has all the health checks, and if I ask for an extra blood or urine test they will do it.
- I didn't realise you can actually go every year.
- I didn't know about well woman appointments.
- I went for a GP appointment for a minor complaint and learned about a much more serious health issue (diabetes) – just being in the doctors surgery can increase the chance that you pick these things up.
- I always have to go for my health check as I have high blood pressure.
- For screening, they send a generic letter to everyone with a leaflet.
- It could be made better with a more accessible leaflet
- I think the age for all this screening needs to be lowered for people with learning disability that cannot communicate.
- Young women who ask for smear tests sometimes cannot get access.
- [Mum said about her daughter]: I take her with me when I need a smear test or another screen, so that she sees what it looks like, and try to lower the anxiety.

What about the issue of consent?

- My daughter refuses, I have persuaded her to go, it's tomorrow.

Access to Screening and health checks for people with learning disabilities 2018

- It would be good if they could see a video explaining more about what to expect.

Is information about smear/mammogram given in school?

- Don't know.
- One school did cover some contraception, they put a condom on the model, but that's about all they did.
- Could a video be put on? At SoLO?
- Might lower the anxiety and nervousness.
- I don't get nervous, I have had the same doctor since I was a child.
- It may be different with a carer rather than mum.
- My mum goes with me, I'm not frightened or scared.
- It comes down to the parent or carer, and carers can change quite often. We need consistency. We need to make sure the carer is well informed, does this come through the care plan?

Do you have a care plan?

- Yes, we have a care plan for her, but it doesn't cover health. It covers how we spend the money – it's called the direct budget.
- They need consistency in the transition from living with parents to supported living.
- They also need the same carer, they can change quite regularly.
- They need to keep your medical records up to date and make sure you go to the annual health check every year.
- Doctors need to make a more conscious effort. It needs to flag up on the system if letters of invitation go unanswered.
- There should be a named contact, who to contact, who is responsible for their health.
- [Mum said about her daughter]: She has a document about what she likes and dislikes and how to communicate with her, in case she goes in to hospital – the Hospital Passport.
- Few in the group have one of these.
- The carers do not have these.

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- Where is the information about what happens to the young person if the carer goes in to hospital?

Focus group close

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