

Improving Health Outcomes for People with Learning Disabilities

A co-produced checklist to support Annual Health Checks

MARCH 2021



Table of Contents

List of Abbreviations	Page 2
Introduction	Page 3
About Healthwatch South Gloucestershire	Page 4
Background	Page 5
Aims and Objectives	Page 8
Method	Page 9
Results and Findings	Page 13
Conclusions	Page 18
Recommendations	Page 19
Stakeholder Responses	Page 20
Appendices	Page 21
Get in touch	Page 26

List of Abbreviations

BNSSG CCG	Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group
CQC	Care Quality Commission
GP	General Practice
HAP	Health Action Plan
HWSG	Healthwatch South Gloucestershire
LD	Learning Disability
LD AHC	Learning Disability Annual Health Check
LeDeR	The Learning Disability Mortality Review Programme
PWLD	People with Learning Disability
SBCP	Southern Brooks Community Partnership
SP	Social Prescribers

Introduction

At Healthwatch South Gloucestershire our purpose is to find out what matters to service users and help make sure their views shape the support they need. We listen to patient experiences, base our work on them and inform commissioners and providers about good practice and areas for service improvement.

This report summarises our co-produced project which sought to look at the different ways Healthwatch could help improve health outcomes for people with learning disabilities.

Executive Summary

Our main outcomes from this project are:

- ➊ We have created a useful tool, which can be used across South Gloucestershire and beyond in the Bristol, North Somerset areas.
- ➋ We are encouraging Health Action Plans to be up to date, so everyone can support PWLD to keep well.
- ➌ We are contributing to the wider work around “improv(ing) the completion of Health Action Plans following an Annual Health Check.”¹
- ➍ We are ensuring services in South Gloucestershire develop “a proactive approach to meeting the health and care needs of the individual.”²
- ➎ We are facilitating conversations which “support (PWLD) to engage with aspects of their healthcare.”³
- ➏ We are working towards the continued improvement of “communication with PWLD and their families.”⁴
- ➐ We are asking services to share the Checklist by sending it to a patient i.e. when they send them an invitation letter for their LD AHC.

Interim outcomes

- ➊ Building relationships with Community groups in South Gloucestershire who work with PWLDs.
- ➋ Building relationships with GP Practices through the GP LD Leads.

Longer term outcomes

We aim to evaluate the success of the tool by asking the following:

- ➊ Number of LD AHC booked in South Gloucestershire.
- ➋ Experience of those having an LD AHC and their family/carers/supporters.
- ➌ Number of Checklists given to patients and used in preparation.

¹ http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf

² http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf

³ http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf

⁴ http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf

- Change in number of people on learning disability register.

About Healthwatch South Gloucestershire

Healthwatch South Gloucestershire's statutory duty and remit, which is laid out in The Health and Social Care Act 2012, is to provide a voice for people who use health and adult social care services, by:

- Enabling local people to monitor the standard of provision of local care services and whether or how local health and social care services could and ought to be improved.
- Obtaining the views of local people regarding their needs for, and experiences of local health and social care services and importantly to make these views known.
- Promoting and supporting the involvement of local people in the commissioning, the provision and scrutiny of local health and social care services.
- Giving people an opportunity to have a say about their local health and social care services, including those whose voice isn't usually heard.
- Making reports and recommendations about how local care services could and ought to be improved. Provide these to commissioners, providers, people responsible for managing or scrutinising local health and social care services. Share with Local Government.
- Taking public views to the people who make decisions - including having a representative on the Health and Wellbeing Board.
- Feeding issues back to government via Healthwatch England and the CQC.

Our outcomes are tracked against a set of key performance indicators by our commissioners at South Gloucestershire Council. Our 2019-2024 contract promised; ***“Healthwatch is committed to promoting equality, and diversity and tackling social exclusion in all our activities. We aim to ensure equitable access to our initiatives and projects for all.”***

Background

Useful Definitions

Learning Disabilities: “A significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development.”⁵

Learning Disability Annual Health Check (LD AHC): “For adults and young people aged 14 or over with a learning disability...You do not have to be ill to have a health check - in fact, most people have their annual health check when they're feeling well.”⁶

Multi-morbidity: “Presence of two or more long-term health conditions”⁷

Justification

It is well recognised that PWLD have poorer physical and mental health compared to others and have a lower life expectancy.⁸ Annual Health Checks for adults with learning disabilities were introduced in England in 2008-9. The aim of these were to improve early detection rates of certain health conditions such as cancer and heart disease. To check that any ongoing treatments were appropriate and to help people with learning disabilities become more familiar with their GP.

“Annual Health Checks can identify undetected health conditions early, ensure the appropriateness of ongoing treatments and establish trust and continuity care.”⁹



The Learning Disability Mortality Review (LeDeR) Programme was commissioned to improve the standard and quality of care for people with a learning disability.¹⁰ Based at The University of Bristol, this programme reviews the deaths of PWLD with a view to improve the standard and quality of care for people with learning disabilities.

The Joint Strategic Needs Assessment for South Gloucestershire identified LD as an important area, specifically mentioning that “health inequalities often start early in life and result, to an extent, from barriers they face in accessing timely, appropriate and effective health care.”¹¹

⁵ http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf

⁶ <https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/>

⁷ <https://www.nice.org.uk/guidance/ng56>

⁸ <https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/>

⁹ <https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/health-check-toolkit.aspx>

¹⁰ <http://www.bristol.ac.uk/sps/leder/>

¹¹ <https://edocs.southglos.gov.uk/jsna2017/pages/adults/learning-difficulties/>

The West of England Academic Health Science Network established The West of England Learning Disabilities Collaborative (LDC) in early 2019 to address the disparity between the age of death for people with learning disabilities and the general population.¹²

The NHS Long Term Plan makes a commitment to reducing the premature mortality of people with a learning disability. NHS England/Improvement have provided funding to Clinical Commissioning Groups (CCGs) to support them to review all deaths of people with a learning disability aged four and over, and to improve services based on what those reviews show. CCGs must work with local health and social care providers to develop and put those local action plans into place. Nationally, research from the LeDeR Review found “a third (34%) of deaths of people with learning disabilities were from treatable medical causes, compared to 8% in the general population - a four-fold difference.”¹³

The total number of people in South Gloucestershire with LD (as of July 2017) are estimated at:¹⁴

- 1,086 people aged 18 and over predicted to have a moderate or severe learning difficulty
- 248 people aged 18-64 predicted to have a severe learning difficulty
- 232 people with learning difficulties in permanent residential care home placements and 28 in permanent placements in care homes with nursing

Data obtained from NHS Digital¹⁵ suggests that for the financial year 2019-20 in Quarter 4 (ending 31st March 2019) 928 PWLD were on the LD Register¹⁶ in South Gloucestershire and 294 received an LD AHC.

Professionals who work with PWLD have raised concerns about the health inequalities PWLD in South Gloucestershire face. One being that not all patients receive pre-LD AHC information, such as a questionnaire. Those that do, are not all receiving the same set of prompts for discussion at their LD AHC. This means there is the potential for PWLD to have differing health outcomes depending on their location.

“We need to see people with a learning disability and/or autism as citizens with rights, who should expect to lead active lives in the community and live in their own homes just as other citizens expect to.”¹⁷



¹² <https://www.weahsn.net/our-work/improving-patient-safety/the-deteriorating-patient/the-west-of-england-learning-disabilities-collaborative/>

¹³ http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf

¹⁴ <https://edocs.southglos.gov.uk/isna2017/pages/adults/learning-difficulties/#:~:text=The%20total%20number%20of%20people,have%20a%20severe%20learning%20difficulty>

¹⁵ <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disabilities-health-check-scheme/england-quarter-4-2019-20>

¹⁶ <https://www.mencap.org.uk/advice-and-support/health/dont-miss-out>

¹⁷ <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

COVID-19

While undertaking this project, the COVID-19 pandemic gripped the world. The death rate of people with learning disabilities in England was up to six times higher from COVID-19 during the first wave of the pandemic than the general population. This could be due to higher likelihood of other health problems like diabetes, respiratory problems, obesity and difficulties recognising symptoms or understanding guidance. This disproportionate impact of COVID-19 on PWLD influenced the nature of the questions included in the pre-check questionnaire.

Aims and Objectives

The project aimed to respond to patient feedback that suggested a lack of information prior to an LD AHC may mean PWLD and their families are not able to get the most out of the service. The project aimed to produce a useful resource for patients, their carers and supporters to help them participate fully in their LD AHC. This tool (which we have called a Checklist) is to be used widely to help people be prepared. The Checklist seeks to support PWLD and their carers to help recognise when things aren't right, take actions to keep healthy, to speak up and seek help. By giving this information in advance, this will help the person understand what their health check is for and what they can get from it.

The Checklist will also help save time and provide consistency at the LD AHC appointment by acting as a prompt for the GP or Nurse. Through asking behaviour change questions, it will give opportunities for prevention and intervention conversations. The Checklist will also support conversations about certain 'embarrassing' health issues, such as sexual health.

The Checklist will also seek to raise awareness and increase uptake of Health Action Plans (HAPs) to help ensure that "people with learning disabilities...have access to universal (mainstream) health services in the same way as the general population, but there (is also) an option to access more LD specific specialist services where required/relevant."¹⁸

The Checklist will be created in an accessible format, using appropriate language and suitable images from Photosymbols.¹⁹ This will be to ensure that everyone involved in the PWLD care can use, understand and benefit from the Checklist. The aim was that the content of the checklist would be compiled and informed by findings from the 2019 LeDeR Review, the focus group, the steering group and an existing resource created by Leeds and York Partnership NHS Foundation Trust²⁰.

The 2019 LeDeR Mortality Review points out there is "a need for professionals to spend more time and care ensuring that families had a good understanding of the issues at stake."²¹



¹⁸ https://bnssgccg-media.ams3.cdn.digitaloceanspaces.com/attachments/bccg_tcp_website_version_11-2016_R9fMn7a.pdf

¹⁹ <https://www.photosymbols.com/>

²⁰ <https://www.learningdisabilityservice-leeds.nhs.uk/get-checked-out/>

²¹ http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf

Method

Co-Production

A co-production approach helped the project stay focused on PWLD, and their families, parents and carers. Co-production is a process that involves the voice of users of services from the very start of a project to its end. This ensures it adequately reflects the needs of the individual, their support network, the education setting needs and the wider community, rather than focusing on the needs of the service. Co-production is an ongoing partnership between people who design, deliver and commission services, people who use the services and people who need them.²²

“We will need to learn how to allow people to determine what is the way they want to tackle areas of their lives rather than prescribing a ‘service’ to meet the ‘need’”²³



Collecting Feedback

In line with the aims and purpose of Healthwatch, this project has looked to include the views, ideas and suggestions of people with lived experience at every available opportunity.

The impact of COVID-19 has meant that we had to change and adjust our methods of engagement at multiple times throughout the development of the project. The primary impact has been on how we conducted our lived experience focus groups. The move to online focus groups has posed many challenges, specifically in creating meaningful engagement opportunities with those with learning disabilities.

Professionals and Carers Steering Groups

We brought together a digital steering group of carers and professionals. This group of people were instrumental in helping form the Checklist. Their combined expertise and experience provided an important insight into the health inequalities PWLD face.

Due to the increased pressures of COVID-19, it was challenging to speak with carers. However, we used Zoom and email feedback to receive input, ideas and

²² https://bnssgccg-media.ams3.cdn.digitaloceanspaces.com/attachments/bccg_tcp_website_version_11-2016_R9fMn7a.pdf

²³ https://bnssgccg-media.ams3.cdn.digitaloceanspaces.com/attachments/bccg_tcp_website_version_11-2016_R9fMn7a.pdf

suggestions from Carers. The following points to consider and question ideas were brought to our attention by those who care for and support PWLD.

Question suggestions and considerations highlighted by Carers:

- “What might have changed since your last LD AHC?”
- Ask about amount of water consumed - can this be any non-alcoholic liquid?
- Ask questions about exercise
- “Top Tips” - opportunity to provide advice around eating and exercise
- Reasonable adjustments
- “What are the Flu vaccination options?”
- “How do you feel about needles?”
- “How do you feel about having your blood taken?”
- “How do you feel about using a Blood pressure cuff?”
- Feelings about Physical contact
- Extra information/top tips about smoking, alcohol and vaping
- Has the carer had a carers review
- Prompt for carer to have NHS Health Checks
- “Are you registered as a carer with you GP?”
- “Have you heard of the Carers Support Centre?”
- “Have you thought about future plans?”
- Be aware of the difference between LD and Additional needs
- ‘Shared Lives Scheme’²⁴
- ‘Stepping Forward Group’²⁵
- Ideal to have a PWLD and Carer leaflet
- One carer felt that their Practice might not send anything out as the PWLD has limited capacity, so wouldn’t be able to complete a ‘checklist’ - they said it would still be useful to receive one to help them be prepared when they support the LD AHC

The Steering Group of professionals met monthly on Microsoft Teams, and kept in regular email contact. The group helped shape and refine the Checklist.

The Steering Group of professionals included:

- *Maisy Griffiths - Area Lead (Healthwatch South Glos)*
- *Lesley Le-Pine - Quality Lead & LeDeR Programme Manager (BNSSG CCG)*
- *Zain Patel - Transformation Manager - LD (BNSSG CCG)*
- *Louise Lees - Specialist Health Improvement Officer (South Glos Council)*
- *Toria Wrangham - Social Prescribing Manager (Southern Brooks)*

Question suggestions and considerations highlighted by the professionals steering group:

²⁴ <https://www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/shared-lives-schemes/>
²⁵ <https://oneyou.southglos.gov.uk/for-your-body/move-more/walking/>

- If you're over 40, you're entitled to physical health check
- Do you know about SBCP Social Prescribers?
- Do you have a Health Action Plan?
- One You South Gloucestershire Wellbeing service
- Amount of water drunk
- Safe exercise/walking?
- What fruit do you eat?
- What reasonable adjustments should be made for the person you care for?
- What do they like? What don't they like?
- LD AHC - can't just be a chat, has to have an outcome
- Can they self-disclose? There might be some adults who have not had a formal diagnosis of LD
- How can we make the whole process more robust?
- People finding hardest to reach are those that live at home with older parents - what can we do?
- Who are you supported or cared for by?
- No provision for carers of adults with LD in South Gloucestershire
- Medication review
- Ensure context and purpose for LD AHC
- HAP is the takeaway outcome

Lived Experience Focus Group

We were supported by Choices4U²⁶ to speak with adults with LD. Due to COVID-19 measures, we were not able to meet the focus group face-to-face. However, Choices4U assisted by facilitating a Zoom meeting at the end of a regular support session. HWSG is incredibly grateful to the team at Choices4U for their support and input.

Question suggestions and considerations highlighted by the lived experience focus group:

- "What is a good heart rate?"
- "It would be nice to be reminded about healthy eating, like 'eat the rainbow'"
- "What does 'calorie control' mean?"
- "How long would it take to burn off a biscuit?"
- "Can you include the Changes4Life²⁷ App?"
- "Can you include simple snack suggestions to encourage people away from crisps?"
- "Can you include home and seated exercises?"
- "Noticing walk" is something I would do

²⁶ <https://www.southglos.gov.uk/leisure-and-culture/sports-clubs-and-centres/sports-development/choices-4-u-guardians-carers-and-funders/>

²⁷ <https://www.nhs.uk/change4life>

- Game exercises such as Nintendo as fun
- “I like the logging in machine”
- “I like being asked if I am okay and if I have been okay”
- “I Like it when I am told why I need to be weighed”
- “I don’t like needles”
- “I get bored when waiting for appointments”
- “I don’t like blood pressure machine - it’s tight and makes loud sounds”
- “I like to be told about the Flu vaccination”

Observations:

- Mixed response from participants about extra information section
- Had good understanding of health and health checks
- Need to make benefits of LD AHC very clear
- Explain what LD AHC is and why it is important for PWLD
- Important for PWLD to know that they can have reasonable adjustments
- Differing pain thresholds
- Find flu jab eligibility “really wordy”
- Like videos about useful things
- Could weight be done at home and taken in?

The 2019 LeDeR Mortality Review says “GP practices need to be proactive and consider if their patients with a learning disability who come unaccompanied to appointments need support to understand their health and options.”²⁸



²⁸ http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf

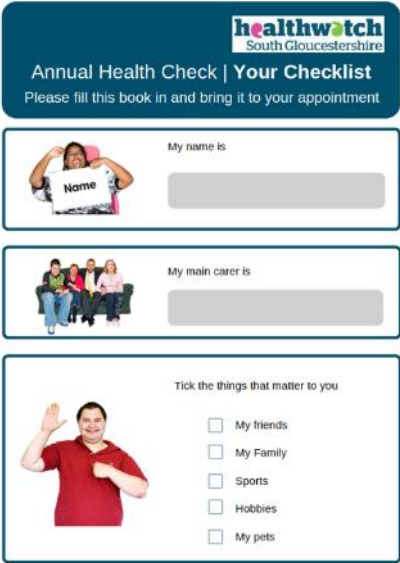
Results and findings

Questionnaire Formation












As a starting point, we identified the five most common long-term health conditions reported in completed LeDeR reviews²⁹:



















- Epilepsy
- Cardiovascular problems
- Dysphagia
- Mental ill health
- Constipation









Following this, we collated themes identified by our Steering Groups and Focus Group. Every theme, and subsequent questions, have wider implications on the health and well-being of PWLD. All the questions have been carefully worded to ensure that they are accessible, and also give the medical professional an opportunity to notice wider patterns of behaviour.

Themes for Questions	Coproduction feedback	Checklist Outcome
<p>Must think about the person</p>	<ul style="list-style-type: none"> • Questions about the PWLD • What they like/don't like • Ask their name • Ask who supports/carers for them • Informed by: https://www.mencap.org.uk/sites/default/files/2017-06/AHC%20Easy%20Read%20Guide%20Final.pdf 	 <p>The screenshot shows a checklist form with the following sections:</p> <ul style="list-style-type: none"> Header: healthwatch South Gloucestershire, Annual Health Check Your Checklist, Please fill this book in and bring it to your appointment. Field: My name is, with a text input box and a small image of a person holding a sign that says 'Name'. Field: My main carer is, with a text input box and a small image of a group of people. Section: Tick the things that matter to you, with a small image of a person in a red shirt and a list of checkboxes: My friends, My Family, Sports, Hobbies, My pets. Page number: Page 1.

²⁹ http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf

<p>General Health</p>	<ul style="list-style-type: none"> 👉 Sleep - impact on mental health 👉 Weight - identify changes 👉 Toilet routines - constipation is a problem 👉 Eyes/dental/hearing can have wider implications on health 👉 Pick up on smoking/drinking habits -prevention/intervention opportunity for GP/Nurse 👉 Exercise - gives a prevention/intervention for GP/Nurse 👉 Informed by: https://www.myhealthguideapp.com/ 👉 Informed by: https://www.mencap.org.uk/sites/default/files/2016-04/ELDSA%20easy%20read%20v1.pdf 👉 Informed by: https://www.england.nhs.uk/wp-content/uploads/2019/05/action-from-learning.pdf 	<div style="border: 1px solid black; padding: 5px;"> <p style="text-align: center; background-color: #0056b3; color: white; margin: 0;">Health</p> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>How many hours do you sleep each night?</p> <input style="width: 100px;" type="text"/> </div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>Do you have any problems when you poo?</p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I Don't Know </div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>Do you have any problems when you wee?</p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I Don't Know </div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>Has your weight changed in the last 6 months?</p> <input type="checkbox"/> ↑ Gone Up <input type="checkbox"/> ↓ Gone Down </div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>Do you have your eyes tested?</p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I Don't Know </div> <p style="text-align: center; font-size: small;">Page 2</p> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>Do you get your teeth checked?</p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I Don't Know </div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px; background-color: #ffe6e6;">  <p>Top Tip: Brush Your Teeth Everyday</p> </div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>Have you had your hearing tested?</p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I Don't Know </div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>Do you smoke?</p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I Don't Know </div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>Do you drink alcohol?</p> <p><i>Alcohol means drinks like beer or wine</i></p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I Don't Know </div> <p style="text-align: center; font-size: small;">Page 3</p> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;"> <p>What exercise do you do each week?</p> <input type="checkbox"/> Walking <input type="checkbox"/> Swimming <input type="checkbox"/> Dancing e.g. Zumba <input type="checkbox"/> Singing in a Choir <input type="checkbox"/> Team Sports <input type="checkbox"/> Other </div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px; background-color: #ffe6e6;">  <p>Top Tip: You can ask for help to get more active at your GP Surgery</p> <p>It's good to do 30 minutes activity every day</p> </div> </div>	<p>Ask about flu vaccination</p>	<ul style="list-style-type: none"> 👉 Gives opportunity to ask about Reasonable Adjustments 👉 Even more important in the context of COVID 	
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	<ul style="list-style-type: none">  Informed by: https://www.gov.uk/government/publications/flu-vaccinations-for-people-with-learning-disabilities/flu-vaccinations-supporting-people-with-learning-disabilities  Informed by: https://www.youtube.com/watch?v=TYgH181Xijs 	<div style="border: 1px solid black; padding: 5px;"> <p style="text-align: center; background-color: #004a7c; color: white; padding: 2px;">Flu Vaccination</p> <div style="display: flex; justify-content: space-between; align-items: flex-start;"> <div style="text-align: center;">  </div> <div> <p>Have you had a flu jab this Winter?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> I Don't Know</p> </div> </div> <div style="border: 1px solid pink; padding: 5px; margin-top: 5px;"> <div style="display: flex; align-items: center;">  <div style="margin-left: 10px;"> <p>Top Tip: If you haven't had one ask your GP or Nurse during your Health Check</p> </div> </div> <p style="text-align: right; font-size: small;">Page 4</p> </div> </div>
<p>Questions about eating and drinking</p>	<ul style="list-style-type: none">  Fruit/veg consumption  Gives intervention opportunity for GP/Nurse  'Eat a rainbow' - empower PWLD to make positive choices  Dehydration is an issue  Gives a chance to talk about importance of water over and above fizzy drinks/hot drinks  Another opportunity to pick up on potential constipation issues 	<div style="border: 1px solid black; padding: 5px;"> <p style="text-align: center; background-color: #004a7c; color: white; padding: 2px;">Eating</p> <div style="display: flex; justify-content: space-between; align-items: flex-start;"> <div style="text-align: center;">  </div> <div> <p>How much fruit do you eat each day?</p> <input style="width: 100px; height: 20px;" type="text"/> </div> </div> <div style="display: flex; justify-content: space-between; align-items: flex-start; margin-top: 5px;"> <div style="text-align: center;">  </div> <div> <p>How many vegetables do you eat each day?</p> <input style="width: 100px; height: 20px;" type="text"/> </div> </div> <div style="border: 1px solid pink; padding: 5px; margin-top: 5px;"> <div style="display: flex; align-items: center;">  <div style="margin-left: 10px;"> <p>Top Tip: To make sure you eat five pieces of fruit and vegetables each day, try to eat the rainbow!</p> </div> </div> </div> <div style="border: 1px solid pink; padding: 5px; margin-top: 5px;"> <div style="display: flex; align-items: center;">  <div style="margin-left: 10px;"> <p>Top Tip: Potatoes do not count as one of your five a day</p> </div> </div> <p style="text-align: right; font-size: small;">Page 5</p> </div> <div style="border: 1px solid black; padding: 5px; margin-top: 5px;"> <p style="text-align: center; background-color: #004a7c; color: white; padding: 2px;">Drinking</p> <div style="display: flex; justify-content: space-between; align-items: flex-start;"> <div style="text-align: center;">  </div> <div> <p>How much water do you drink each day?</p> <input style="width: 100px; height: 20px;" type="text"/> </div> </div> <div style="border: 1px solid pink; padding: 5px; margin-top: 5px;"> <div style="display: flex; align-items: center;">  <div style="margin-left: 10px;"> <p>Top Tip: You should drink 10 glasses of water a day</p> </div> </div> </div> <div style="border: 1px solid pink; padding: 5px; margin-top: 5px;"> <div style="display: flex; align-items: center;">  <div style="margin-left: 10px;"> <p>Top Tip: Fizzy drinks do not count towards your 10 glasses of water</p> </div> </div> </div> <div style="border: 1px solid pink; padding: 5px; margin-top: 5px;"> <div style="display: flex; align-items: center;">  <div style="margin-left: 10px;"> <p>Top Tip: Hot drinks do not count towards your 10 glasses of water</p> </div> </div> <p style="text-align: right; font-size: small;">Page 6</p> </div> </div> </div>

<p>Health Screenings</p>	<ul style="list-style-type: none"> 👉 These are often missed 👉 Often an ‘embarrassing’ topic 👉 Needs to be explained in an accessible way 👉 Opens up the conversation for GP/Nurse 	<div style="border: 1px solid black; padding: 5px;"> <p style="text-align: center; background-color: #0056b3; color: white; padding: 2px;">Health Screening - Female</p> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>A smear test is a check to make sure your cervix is healthy.</p> <p>Your cervix is in your vagina.</p> <p>Have you had a smear test?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> I Don't Know</p> </div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>Do you check your own boobs?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> I Don't Know</p> </div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>Have you had any changes in your period?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> I Don't Know</p> </div> <p style="text-align: center; background-color: #0056b3; color: white; padding: 2px;">Health Screening - Male</p> <div style="border: 1px solid black; padding: 5px;">  <p>Do you check your own testicles?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> I Don't Know</p> </div> <p style="text-align: right; font-size: small;">Page 7</p> </div>
<p>Sexual Health</p>	<ul style="list-style-type: none"> 👉 PWLD have sexual health needs 👉 Informed by: https://www.mencap.org.uk/advice-and-support/relationships-and-sex 👉 Informed by: https://lifesupportproductions.co.uk/2019/09/20/you-your-body-growing-up-relationships-and-sex/ 	<div style="border: 1px solid black; padding: 5px;"> <p style="text-align: center; background-color: #0056b3; color: white; padding: 2px;">Sexual Health</p> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>Do you have sex with a partner?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> I Don't Know</p> </div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>Do you use condoms?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> I Don't Know</p> </div> <div style="border: 1px solid black; padding: 5px;">  <p>Top Tip:</p> <p>Mencap have lots of information about sex and relationships</p> </div> </div>
<p>Social Prescribing</p>	<ul style="list-style-type: none"> 👉 PWLD might not be aware of the service 👉 SP offers another route to share the Checklist with PWLD 👉 Good intervention or prevention opportunity around mental health and wellbeing 👉 How to access service - Referral via GP 👉 Informed by: https://www.nhs.uk/oneyou/ho 	<div style="border: 1px solid black; padding: 5px;"> <p style="text-align: center; background-color: #0056b3; color: white; padding: 2px;">Social Prescribing</p> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">  <p>Social prescribing is about helping people to stay healthy by getting involved in their local community.</p> <p>Social prescribing Link Workers support people to do this.</p> </div> <p style="text-align: right; font-size: small;">Page 8</p> </div>

[w-are-you-quiz/#EgH2JmspGQv5Ldyf.97](https://www.healthwatchsouthgloucestershire.org.uk/w-are-you-quiz/#EgH2JmspGQv5Ldyf.97)

How have you been feeling over the last week?

Very Happy Happy Neutral Sad Really Sad

Have you been worried over the last week?

Not Worried A bit Worried Fairly Worried Worried a lot Worried all the time

Would you like help to find new friends?

Yes
 No
 I Don't Know

Do you want help finding a hobby or a job?

Yes
 No
 I Don't Know

Do you and your carer understand what help you should be getting?

Yes
 No
 I Don't Know

Top Tip:
Link workers are based at GP Practice. Ask your GP or Nurse during your Health Check to be referred.

Page 9

Health Action Plan

- Important outcome from LD AHC
- Checklist is feeding into this aim
- Important that HAP is discussed during LD AHC
- Important to give PWLD the chance to engage in conversations about consent

Health Action Plan

Have you got a Health Action Plan?

Yes
 No
 I Don't Know

Can we share your plan with other staff?

Yes
 No
 I Don't Know

Top Tip:
If you don't have one, ask your GP or Nurse during your Health Check

Page 10

<p>Questions for carer/supporter</p>	<ul style="list-style-type: none"> ➤ Important part of PWLD life ➤ What they are entitled to ➤ Prompts for carer/supporter and GP/Nurse ➤ Medicines - where many taken, instead of asking carer to list, gives a prompt for discussion with GP/Nurse ➤ Opportunity for prevention or intervention around mental health and wellbeing 	<div style="background-color: #004a7c; color: white; padding: 5px;"> <p>Questions for Carers and Supporters</p> <p>Please answer these questions to make sure the doctor or nurse knows as much as they can about the person you care for. <i>(or, if you are able to, fill these in for yourself)</i></p> </div> <div style="background-color: #e0e0e0; padding: 5px; margin-bottom: 5px;"> <p>What reasonable adjustments should be made for the person you care for?</p> <p><input type="checkbox"/> They would prefer a nasal spray e.g. for flu vaccination</p> <p><input type="checkbox"/> They have a high or low pain threshold</p> <p><input type="checkbox"/> They do not like needles</p> <p><input type="checkbox"/> They do not like the manual Blood Pressure Cuff</p> <p><input type="checkbox"/> They do not like the digital Blood Pressure Cuff</p> </div> <div style="background-color: #e0e0e0; padding: 5px; margin-bottom: 5px;"> <p>Are there other reasonable adjustments that could be made? e.g. flexible appointment times, quiet waiting rooms, specific communication needs</p> </div> <div style="background-color: #e0e0e0; padding: 5px; margin-bottom: 5px;"> <p>Please tell the GP or Nurse the medications the person you care for takes and if there have been any changes.</p> </div> <div style="background-color: #e0e0e0; padding: 5px; margin-bottom: 5px;"> <p>What has changed since the last Health Check? e.g. mobility, family member passed away, behaviour, sleep routine</p> </div> <div style="background-color: #e0e0e0; padding: 5px; margin-bottom: 5px;"> <p>Are you a paid or unpaid carer?</p> </div> <div style="background-color: #e0e0e0; padding: 5px; margin-bottom: 5px;"> <p>Are you registered as a carer with the GP? Yes / No</p> </div> <div style="background-color: #e0e0e0; padding: 5px; margin-bottom: 5px;"> <p>Have you had a carers review? Yes / No</p> </div> <p style="text-align: center; font-size: small;">Page 11</p> <div style="background-color: #e0e0e0; padding: 5px; margin-bottom: 5px;"> <p>Is there anything you are worried about or would like to ask? It could be about you or the person you care for.</p> </div>
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Conclusions

This project has produced a Checklist which is a resource that seeks to improve the quality of the LD AHC and the health outcomes for PWLD by offering multiple opportunities for prevention and intervention conversations. By adopting a co-production approach, the Checklist has had buy-in from health and care professionals, carers and, most importantly, PWLD.

The latest data from Public Health for 2020/21 tells us that of those eligible for an LD AHC in the Bristol, North Somerset and South Gloucestershire area, only 36% took one up. This compares to 37% in the South West region and 50% for England. While this could be an outlier, especially with the impact of the COVID-19 pandemic, these figures demonstrate a need for this Checklist to help promote uptake of LD AHC.

To conclude, this resource provides accessible information that will promote better health conversations between PWLD, their carers/supporters and their GP/Nurse for the long-term benefit of this under-served population.

The full 'Checklist' can be found here:

<https://www.healthwatchsouthglos.co.uk/LDAH-Checklist>

Recommendations

We believe the following six recommendations to be achievable, affordable and evidence based:



That the Checklist is placed on TeamsNet and Remedy as a resource for professionals



That the Checklist is shared widely between Voluntary Sector Partners



That services promote the resource on social media to encourage conversations around LD AHC and HAPs



That steps are taken to ensure GPs and Practice Managers make good use of the Checklist by sharing with PWLDs and their carers



That the Sirona Community Learning Disability Team utilise the Checklist in their work



The Checklist is integrated into systems in the Bristol & North Somerset areas for the benefit of all PWLDs

Stakeholder Responses

Cllr. Ben Stokes, Chair Health and Wellbeing Board South Gloucestershire and Chair Learning Disabilities Partnership Board:

“The Annual Learning Disabilities Health Check is a key tool to helping tackle some of the systemic inequalities that exist in getting access to healthcare for people with Learning Disabilities (LD).

I hope that the relevant health and care professionals will be able to accept the report’s recommendations for the widespread use of the newly designed Health Check Checklist. The report also spells-out the significant variation in take-up and quality of service between GP practices in South Gloucestershire.

It is very disappointing that these largely avoidable variations exist and confirms what people with LD and their carers have been telling us for a long time, that “many GPs don’t seem to take the health needs of people with LD seriously”. The checklist will surely help to make the whole process of the Annual Health Check not only easier but also more effective at reaching a broader spread of people with LD.”

Louise Hudson, Locality Development Manager, South Gloucestershire, NHS Bristol, North Somerset & South Gloucestershire CCG:

“What a brilliant piece of collaborative work - after putting you all in touch with each other earlier in the year and then stepping away it’s great to see the end result.”

Lesley Le-Pine, Bristol, North Somerset & South Gloucestershire CCG:

“This was a fantastic piece of partnership working with Healthwatch and social prescribing - really brilliant. They involved and tested with service users and it provides a great 'get ready' checklist to roll out across BNSSG. Highly recommended - would use again!”

Appendix 1

Equality Impact Assessment

Project Name: Improving Health Outcomes for People with Learning Disabilities
A co-produced checklist to support Annual Health Checks

Date of Assessment: 2020

Equality issues were identified in the scoping phase of the project to identify overlapping characteristics that impact this group and those that care for them. These have helped to inform our outcomes and recommendations;

Equality Group	Negative Impact	Positive Impact	No Impact	Unsure of Impact	Reason(s)
PWLD - lived experience	yes	-	-	-	Our patient feedback reports in 2020 heard about the lived-experience of PWLD and their carers. Concerns were raised about the lack of appropriate, accessible information, specifically in relation to health checks. See listed sources of information and reasons why this project was selected as a priority for action, including health disadvantages for PWLDs - report pages 6-7
Carers	yes	-	-	-	NICE Quality Standards (March 2021) recommend that carers are supported to actively participate in decision making and planning for the person they care for. https://carers.org/news-and-media/news/post/114-nice-guidance-on-providing-high-quality-support-for-adult-carers
Women/ Girls	yes	-	-	-	On average, the life expectancy of women with a learning disability is 18 years shorter than for women in the general population. (Mencap)
Men/ Boys	yes	-	-	-	On average life expectancy for boys and men with a Learning Disability is 14 years shorter than men in the general population. (Mencap)
LGBTQ+	yes	-	-	-	Their needs are often overlooked, particularly mental health needs.
White People	yes	-	-	-	Disadvantage occurs if the white person experiences socio-economic deprivation as this is known to inhibit/affect healthy lifestyle choices.
BAME	yes	-	-	-	People with learning disabilities from black and minority ethnic communities face 'double discrimination' in accessing public services (NICE.org.uk)

					<p>https://raceequalityfoundation.org.uk/wp-content/uploads/2018/03/health-brief15-1.pdf</p> <p>Support for language skills both for those who have low verbal ability and those service users, families and carers who may have difficulty with English (NICE.org.uk)</p>
Physical Disability					<p>People with learning disabilities have a much greater propensity to develop health problems - both physical and mental health, as compared with the general population. (Foundation for people with LDs) There are additional challenges & service needs for those with profound disabilities, particularly individuals who are non-verbal or have a mental health disability too (NICE.org.uk)</p> <p>Problems associated with ‘diagnostic overshadowing’, where the learning disability trumps the physical or mental health need. Causes concern if professional misses the clues from symptoms presented. https://www.ghc.nhs.uk/files/A%20Z%20of%20Health%20Issues%2020120.pdf</p>
Faith Groups	-	-	x	-	It is not anticipated that there would be a likelihood of people being proportionately more or less impacted as a result of their faith
Pregnancy & Maternity	x	-	-	-	Nationally 7% of people with a learning disability are parents, and many have a mild impairment. 40% of these parents don’t live with their children. Impact from not receiving suitable antenatal care and education. (Best beginnings)
Marriage & Civil Partnership	-	-	x-	-	It is not anticipated that there would be a likelihood of people being proportionately more or less impacted as a result of marriage or civil partnership.

Appendix 2

Project Logic Model.

Your Project Title: Learning Disability Annual Health Checks – user led improvement of pre-check questions

The issue

Who does this affect? What problem(s) are they facing? What evidence do you have about this problem? [Evidence of the problem] For example, scale and trends in the problem reported in research and policy

- People with a learning disability (PWLD) often have poorer physical and mental health than other people
- Problem = not all people receive a pre-visit questionnaire, and the questions are not asking about general health
- PWLD is a JSNA priority in South Gloucestershire
- Nationally ¼ of people with LD attend their LDAHC, NHS England want to bring this up to 75%

Project aim and objectives

Contribute towards improving health outcomes for people with LD; specifically ensuring that PWLD get the most out of their LD AHC and come away with a Health Action Plan

Focus and scope

What is the location, setting, target and duration of your project?

- Location = South Gloucestershire
- Setting = Focus groups
- Target = People with LD and their carer/supporters
- Duration (heavily impacted by COVID-19 Pandemic): August/September = focus groups
- October = create checklist
- November/December = release checklist
- Early 2021 = write up report?

Inputs

What financial and non-financial resources are committed to the project? Include contributions from partners

- Sirona
- South Glos Council
- South Glos Public Health
- Milestone Trust
- Paul's Place
- The Hive
- BNSSC CCG
- Other community groups

Activities

What will your project do?

- Co-produce a pre-check questionnaire to include more information to help patient and GP
- Organise focus groups with PWLD and Carers/professionals
- From the focus groups shape the project and outcome.
- Meet regularly with professionals to evaluate and monitor project direction

Outputs

What are the services, goods and products that will arise from project activities?

- Updated questionnaire that is useful, accessible, and co-produced
- Realistic recommendations
- Publication of a report
- Publication of finding on our media and newspaper coverage
- Report and recommendations forwarded to services providers and commissioners

Evidence of the solution

What evidence makes you think this will work?

- Great interest from partners and stakeholders
- Involvement with services users and partners
- Enough evidence and data to support the project proposal

Context/Risks

How might key processes and events help or hinder your project activities?

- Creating accessible information
- Engaging successfully with PWLD
- What is or is not already sent out by Primary Care
- Team capacity

Intended impacts

What are the links between your outcomes and the big impacts that you and your supporters want to create?

- Give a strong voice to those who may not be able to do it before
- Find out what the mains health issues for PWLD are
- Provide qualitative insights about the needs of PWLD
- Improve the health outcomes for PWLD
- Bring together professionals and PWLD to cover multiple different angles
- Reduce health inequalities for PWLD

Main intended outcomes

What outcomes would you expect to see if change is successful? Pick THREE

How will you measure them?

1. Increased uptake of LD AHC - compare numbers before and after project
2. Used across South Gloucestershire - follow up and see which Practices use/circulate
3. Encourage positive conversations around health/welbeing to help counteract multi-morbidity - harder to measure but could be followed up qualitatively

Interim intended outcomes (quick wins)

What short term changes would you expect to see? These are stepping stones to your main intended outcomes

How will you measure them?

- Build relationship with Community groups in South Gloucestershire who work with PWLDs – follow on social media, subscribe to email lists, join meetings/support groups
- Build relationships with GP Practices through the GP LD Leads – email communication, follow on social media (where it exists)
- Coverage of the project findings and recommendations in local media outlets, websites, FB, etc.

Appendix 3

Letter to Primary Care services



To all GP Practice and Primary Care Professionals |

RE: New Checklist to help people with learning disabilities get the most from their Annual Health Check

This 'Checklist' is for patients and their carers/supporters to fill in before their Annual Health Check. Please promote the use of this tool widely to help people prepare for their annual health check with your practice. This helps to save time by giving you information in advance and helps the person understand what their health check is for.

Our ask:

- ✓ Share the checklist – please send it to patients when you send them an invitation letter to their Annual Health Check. It is available on TeamsNet and Remedy or can be downloaded here.
- ✓ Encourage people to keep their Health Action Plans up to date so everyone working with the person can support them to keep well - e.g., CLDT, Social Prescribers, day services, carers and family, the One You South Gloucestershire service.

Why this is important: The death rate of people with learning disabilities in England was up to six times higher from COVID-19 during the first wave of the pandemic than the general population. This could be due to higher likelihood of other health problems like diabetes, respiratory problems obesity and difficulties recognising symptoms and understanding guidance. (*Deaths of people identified as having learning disabilities with COVID-19 in England in the Spring of 2020*)

Background: Healthwatch South Gloucestershire have worked with BNSSG CCG, Southern Brooks Community Partnerships and South Gloucestershire Council to look at how to improve the quality of the annual health check and as a result a new checklist was developed. The content of the checklist has been developed in collaboration with a focus group of people with learning disabilities, and a steering group of carers, supporters and professionals.

The Checklist: This supports people with learning disabilities and their carers to help recognise when things aren't right, take actions to keep healthy, to speak up and seek help. This checklist will be used to promote take-up of Annual Check-ups, raise awareness of their importance and contribute towards improving the health outcomes for those with LD. It will also raise awareness of Health Action Plans, highlighting factors that are sometimes missed (such as constipation) and the importance of health screenings (such as breast and testicular cancer).

Kind Regards,

Maisy Griffiths	Lesley Le-Pine	Zain Patel	Toria Wrangham	Louise Lees
Area Lead (Healthwatch SG)	Quality Lead & LeDeR Programme Manager (BNSSG)	Transformation Manager - LD (BNSSG)	Social Prescribing Manager (Southern Brooks)	Specialist Health Improvement Officer (South Glos Council)



Appendix 4

Breakdown by GP Practice for Quarter 4 (ending March 31st 2019)

GP Practice	The number of patients aged 14 years or over in the financial year on the practices agreed learning disabilities register.	Quarterly count of registered patients aged 14 years or over, at the 31 March 2019, on the practice's Learning Disability register who have received a learning disability health check by the GP practice and have not received a health check in a previous quarter in this financial year.
ALMONDSBURY SURGERY	No figure provided	0
BRADLEY STOKE SURGERY	37	10
CADBURY HEATH HEALTHCARE	46	3
CLOSE FARM SURGERY	27	5
CONCORD MEDICAL CENTRE	53	26
CONISTON MEDICAL PRACTICE	No figure provided	7
COURTSIDE SURGERY	32	9
EMERSONS GREEN MEDICAL CENTRE	27	1
FROME VALLEY MEDICAL CENTRE	43	14
HANHAM HEALTH	69	7
KENNEDY WAY SURGERY	31	14
KINGSWOOD HEALTH CENTRE	62	4
LEAP VALLEY MEDICAL CENTRE	58	18
ORCHARD MEDICAL CENTRE	106	58
PILNING SURGERY	24	10
ST MARY STREET SURGERY	42	0
STOKE GIFFORD MEDICAL CENTRE	71	14
STREAMSIDE SURGERY	15	0
THE DOWNEND HEALTH GROUP	125	42
THORNBURY HEALTH CENTRE - BURNEY	No figure provided	14
THREE SHIRES MEDICAL PRACTICE	No figure provided	2
WELLINGTON ROAD SURGERY	16	12
WEST WALK SURGERY	44	24
TOTAL	928	294

Get in touch



Healthwatch South Gloucestershire
3rd Floor
The Sion
Crown Glass Place
Nailsea
BS48 1RB



07944 373 235



contact@healthwatchsouthglos.co.uk



www.healthwatchsouthglos.co.uk



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Date: March 2021

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