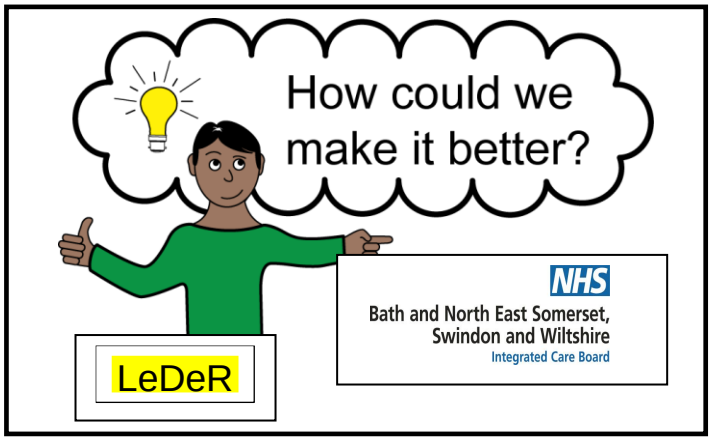
NHS
Bath and North East Somerset, Swindon and Wiltshire
Integrated Care Board

Learning from Lives and Deaths - People with a Learning Disability and Autistic People (LeDeR) Annual Report



1st April 2022 to 31st March 2023

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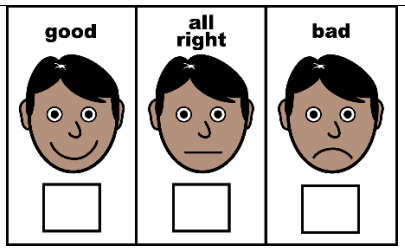
Executive Summary

LeDeR is a non-mandated service improvement programme which aims to improve care, reduce health inequalities, and prevent premature mortality for people with a learning disability and autistic people, by reviewing information about the health and social care support received and producing online reviews using a set template, to identify case specific and thematic learning which:

	**Informs local service improvement using learning from LeDeR reviews, highlighting good quality care and areas requiring improvement.**
	**Drives local service improvements based on themes emerging from LeDeR reviews at a regional and national level.**
	**Influences national service improvements via actions that respond to themes commonly arising from analysis of LeDeR reviews.**

This report is written to summarise analysis of the 2021-22 LeDeR data available, celebrate collective system action progress, triangulate with the local health and care system intelligence, and identify the key action priorities and next steps required during 2023- 2024.

This report also **includes easy read headlines to include accessibility for people with a learning disability to this report**. An Easy Read newsletter will be created for people once this report is published; to help people understand how to stay healthy and well.

(Easy Read pictures are included with consent from Easy on the I and Easy Health.Org)

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National Priorities and LeDeR: Triangulating Requirements

NHS Long Term Plan 2019
The Long Term Plan (LTP) was developed to '*make the NHS fit for the future, and to get the most value for patients'.*

Chapter two of the NHSE Long Term Plan looks at health inequalities and sets out the ambition that people with a learning disability and autistic people *'get better support'.*

Page 52 of the plan specifically focuses on learning disability and autism:

- *'Action will be taken to tackle the causes of morbidity and preventable deaths in people with a learning disability and for autistic people.*
- *The whole NHS will improve its understanding of the needs of people with learning disabilities and autism and work together to improve their health and wellbeing.*
- *Reduce waiting times for specialist services.*
- *Children, young people and adults with a learning disability, autism or both, with the most complex needs, have the same rights to live fulfilling lives.*
- *Increased investment in intensive, crisis and forensic community support*
- *We will focus on improving the quality of inpatient care across the NHS and independent sector'.*

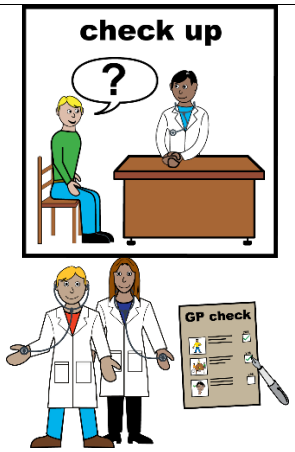
Easy Read Long Term Plan Link:

https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/easy-read-long-term-plan-v2.pdf

NHSE 2023-24 Operational Planning Guidance

The 2023/24 NHS Priorities and Operational Planning Guidance makes clear the aim to deliver the ambitions in the NHS Long Term Plan; including *'our core commitments to improve mental health services and services for people with a learning disability and autistic people'.*

There are two key Long term Plan and Transformation objectives with the planning guidance and BSW ICB work collaboratively to benchmark and improve outcomes and experience for people:

	**Annual Health Check and Plan** 1. *Ensure 75% of people aged over 14 on GP learning disability registers receive an annual health check and health action plan by March 2024*
	**Avoiding and reducing specialist hospital admissions** 2. *Reduce reliance on inpatient care, while improving the quality of inpatient care, so that by March 2024 no more than 30 adults with a learning disability and/or who are autistic per million adults and no more than 12–15 under 18s with a learning disability and/or who are autistic per million under 18s are cared for in an inpatient unit.*

Link https://www.england.nhs.uk/wp-content/uploads/2022/12/PRN00021-23-24-priorities-and-operational-planning-guidance-v1.1.pdf

Reasonable Adjustments

Under the Equality Act 2010 umbrella, anticipatory 'reasonable adjustments' are required by public sector organisations to ensure that services are accessible to disabled people under the Accessible Information Standard
https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/

Over the last few years, the LeDeR programme has recognised a need to improve the recognition and meeting of the needs of people with a learning disability such as:

- reading or writing
- explaining symptoms or a sequence of events
- understanding new information or taking information in quickly
- remembering basic information such as date of birth, address, health problems and appointments
- managing money
- understanding and telling time
- understanding how to prevent ill health and managing any health needs.

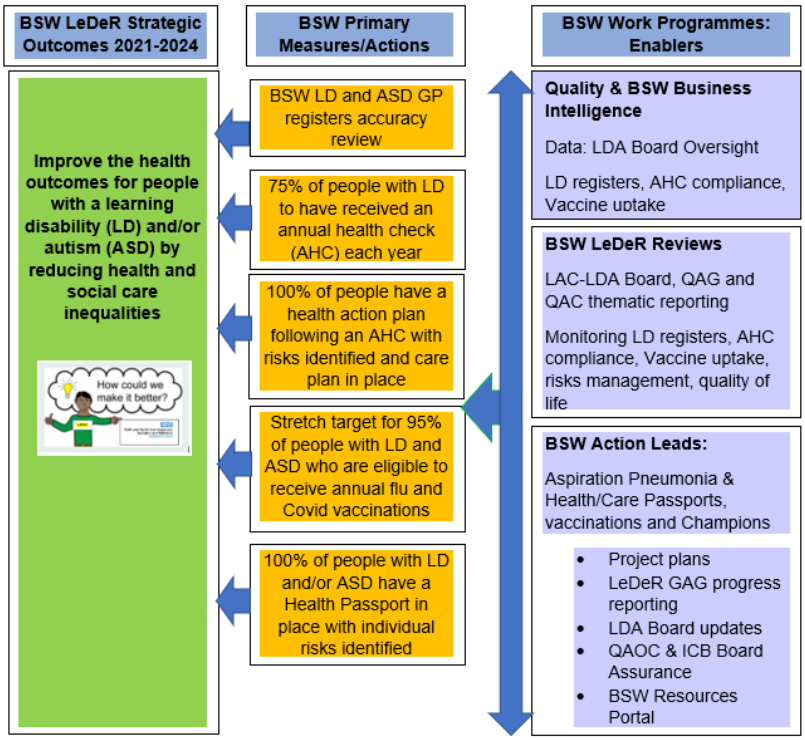
This report therefore also includes Easy Read in key areas to support inclusion.

BSW LeDeR Three Year Strategy Plan 2021-24

NHSE required each ICS to write and submit a three-year plan in 2021, to identify and progress LeDeR learning into action. BSW submitted a strategy plan which was subsequently approved (with the caveat that the proposed priorities would be reviewed over the next three years to ensure timely adaptability to system need). The strategy included BSW key objectives to work with social care to improve the lives and wellbeing for people, prevent ill health, address inequalities, enhance coproduction and personalisation and embed BSW LeDeR learning action. BSW have progressed this strategy.

The strategy was also translated into an Easy Read document in 2022 and will be reviewed in 2023-24 by the BSW Learning Disability and Autism (LDA) Governance Assurance Group. It is expected that a future LeDeR Strategy will be required by NHS England in 2025-28.

A BSW LeDeR draft driver diagram (structured quality improvement chart) was created which highlights the strategic outcomes to reduce health inequalities:



Reasonable Adjustments Flag: NHS Digital Pilot Update

NHS Digital have built and trialled a flag within the NHS; to enable health and care professionals to record, share and view details of reasonable adjustments needs, to further support meeting the Accessible Information Standard: https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/

Online information now states that integration work will be rolled out by the end of 2023, after which the capability is expected to be available to health and social care: https://digital.nhs.uk/services/reasonable-adjustment-flag

See appendix B for the BSW LeDeR Reasonable Adjustments prompts which has been shared with providers.

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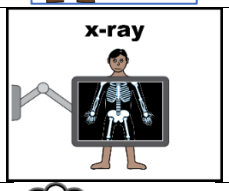
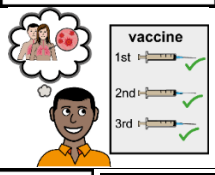
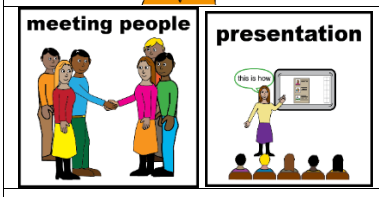
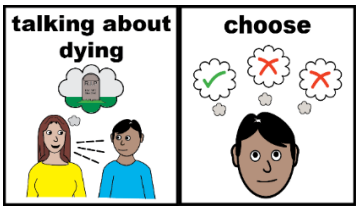
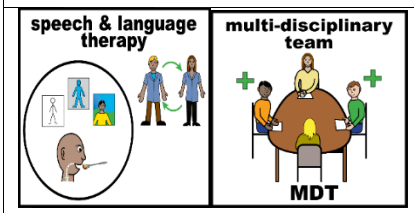
BSW LeDeR Key Achievements in 2022-23 in Easy Read:

	**Improving system working with the acute hospitals, mental health provider and wider care system**
	**Improving the numbers of annual health checks in BSW working with the lead GP and project group**
	**Identifying action required to improve planned access to diagnostics in all three acute hospitals**
	**Increase Covid vaccinations for people with a learning disability**
	**Sharing LeDeR information learning across health and social care**
	**Worked with the End of Life Alliance; improve access to specialist care, and support people to choose what they would like to happen when they are dying**
	**Held meetings to understand why people get aspiration pneumonia.** **Attended a South West Dysphagia Action Group**
	**Held workshops about using Health/Hospital Passports to meet people's needs.** **BSW are now members of a national LeDeR passports group**

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BSW LeDeR (Proposed) Learning Actions for 2023-24 Headlines:

This report will be presented to the BSW LeDeR Quality Assurance Group; BSW Learning Disability and Autism Programme Board; BSW Quality Assurance and Outcomes Committee and BSW ICB Board, to agree and monitor the priority actions as proposed, based on the latest data learning which is:

<table>
<tr>
<td> 


Swallowing Problems (Dysphagia)
Dysphagia knowledge & skills – a collaborative piece of work to develop South West guidance to support carers</td>
<td>Sharing the South West Dysphagia ‘Knowledge and Skills’ document with all BSW providers of care (as dysphagia training is not mandatory to ensure staff know what to do)</td>
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<tr>
<td> 
</td>
<td>Helping social care providers to recognise and report earlier when people are unwell using:
RESTORE2
Recognise Early Soft Signs, Take Observations, Respond, Escalate</td>
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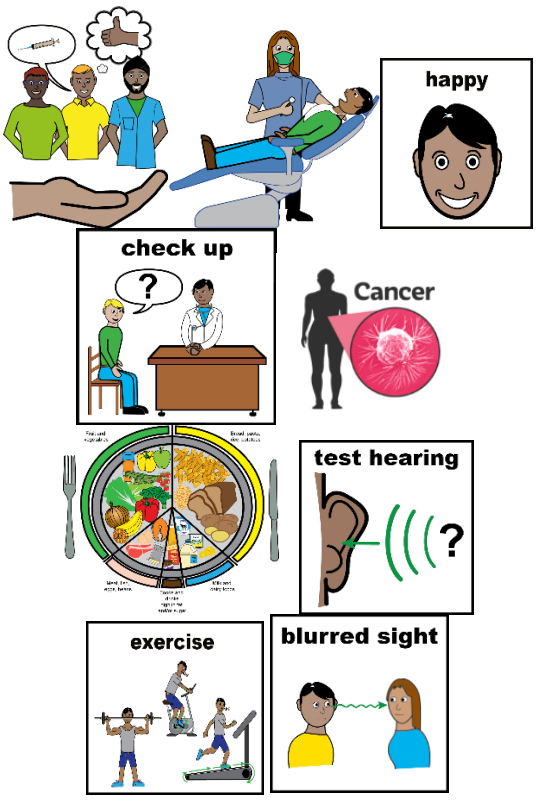
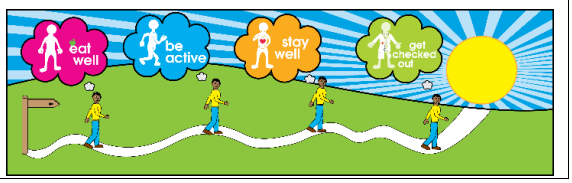
<td> 
</td>
<td>Continue BSW system wide guidance and information on how to help people (and their family/carers) to stay healthy, happy and well including:
• Annual Health Checks and action plans
• Vaccinations
• Cancer screening and prevention
• Dental, hearing and eye checks
• Diet and exercise
• Hobbies and enjoyable activity
 
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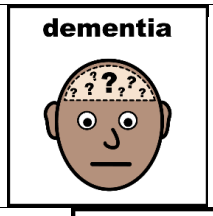
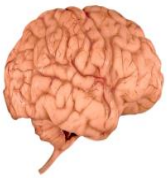
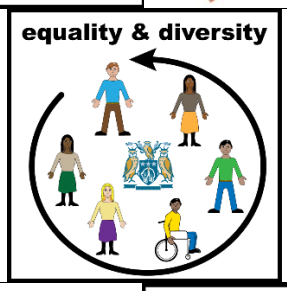
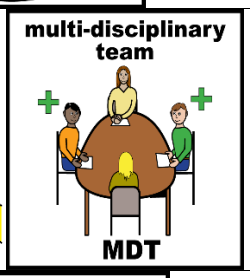
 	**Information sharing to recognise, report, diagnose and provide support to people with early signs of dementia**
	**Work with minority ethnic community groups to identify and remove barriers to diagnosis, specialist care and support**
 	**Recruit a dedicated BSW expert reviewer team via the Integrated Care System to meet the national LeDeR Policy**
	**Look at how to increase the involvement of families in reviews (who often do not respond to LeDeR requests)**

ICB Report Publication Required
As per previous years, this report will be published on BSW ICB website.

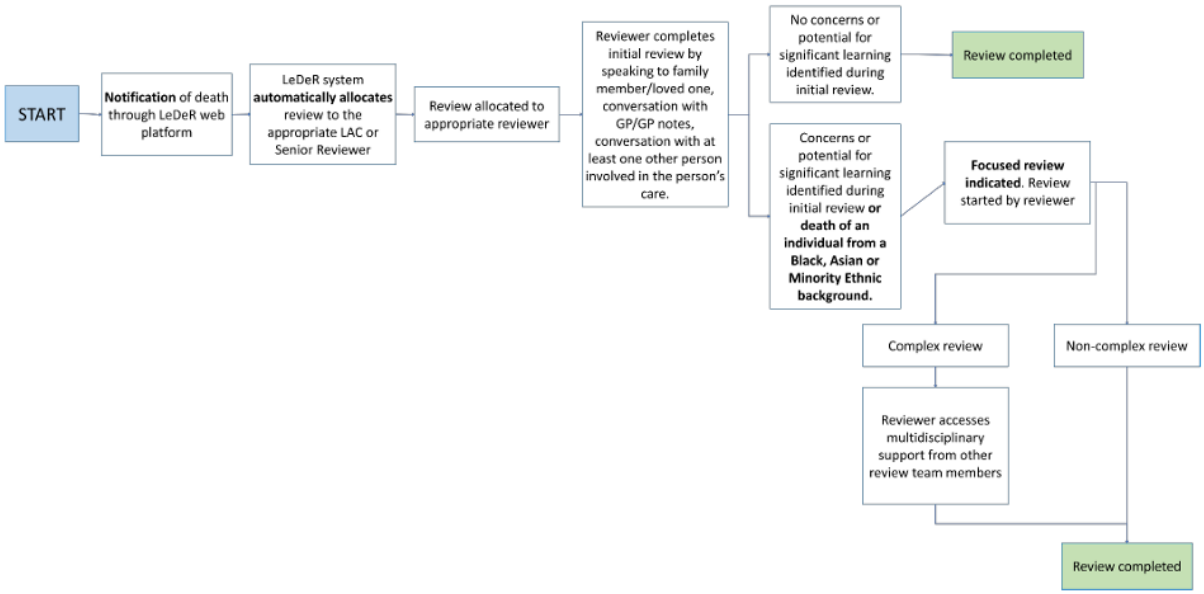
1. Introduction and Context

1.1 The Learning from lives and deaths-People with learning disability and autistic people (LeDeR) programme is funded by NHS England. It is the first national programme of its kind in the world and commenced due to health inequalities:

https://www.england.nhs.uk/wp-content/uploads/2021/03/LeDeR-Policy-2021-Easy-Read.pdf

1.2 **LeDeR Process**:
LeDeR requires notifications to be made following the death of people, and review is undertaken to seek learning and action to reduce the risk of future premature and avoidable deaths.

Figure 1: LeDeR review process overview



1.3 The national LeDeR system does not currently share any data analysis, so all systems are required to collate and manage local data systems. NHS England are developing a national data tool which is anticipated to provide some data, but local data collection will still be required in parallel.

1.4 LeDeR Background and History

LeDeR was first established in 2015 as a response to the recommendations from the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD, 2013). CIPOLD reported that people with learning disabilities are three times more likely to die from causes of death that could have been avoided with good quality healthcare (following previous Mencap reports called Death by Indifference, which exposed institutional discrimination).

CIPOLD Report Link: https@//www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf

1.5 The Department of Health and Social Care previously published a government response to LeDeR aligned to the recommendations in the NHS Long Term Plan as documented in the executive summary.

1.6 The Oliver McGowan campaign was championed by Oliver's mother following learning from his tragic LeDeR review. National training is being rolled out in 2023 as a result of the learning and BSW have progressed this at pace:
Oliver McGowan | Oliver's Campaign |

2. BSW LeDeR Programme; Health Inequalities

2.1 BSW LeDeR Inequality Priorities and The Public Sector Equality Duty

2.2 The Public Sector Duty

The Duty came into force in April 2011 which requires public sector bodies to have due regard to the need to achieve the objectives set out in the Equality Act 2010 to:

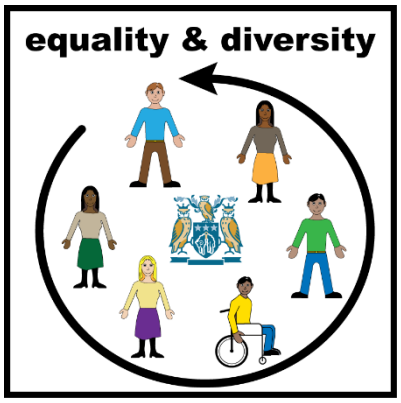
(a) eliminate discrimination, harassment, victimisation, and any other conduct that is prohibited by or under the Equality Act 2010.

(b) advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it.

(c) foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

To ensure transparency, and to assist in the performance of this duty, the Equality Act 2010 (Specific Duties) Regulations 2011 require public authorities, named to publish:

- Equality objectives, at least every four years (from 6th April 2012)
- Information to demonstrate compliance with the public sector equality duty (from 31st January 2012)



2.3 The BSW LeDeR Local Area Coordinator (LAC) is a member of the BSW Inequalities Group and wrote the ICB 2021-22 Annual Equality and Inclusion Assurance Summary Report to include the following 2022-26 ICB equality objectives which are also aligned to broader LeDeR learning actions including health and inequalities assessment, targeted action delivery and accuracy of population demographics:

Number	BSW ICB Objectives 2022-2026
1	Approve and mandate the use of a BSW ICB and ICS standard Equality and Quality Impact Assessment (EQIA) format process; to ensure that quality, equality, and the 9 protected characteristics are considered in all ICB business.
2	Develop and deliver on targeted system and locality 'place-based' equality priorities, with formal Board reporting and action evidence of the Core20PLUS5 to: • reduce health inequalities • make reasonable adjustments • remove barriers to accessing care and support within BSW https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/core20plus5/
3	Improve the accuracy of health and social care demographics and coding; to ensure that the population data and associated health needs are precisely collated and responded to.

2.4 BSW LeDeR Equality and Quality Impact Assessment

A BSW LeDeR specific Equality/Quality Impact Assessment (EQIA) was undertaken later in quarter 4 in 2021-22 and shared with the LeDeR Quality Assurance Group members (undertaken in response to the change in national LeDeR policy). This reframed the LeDeR inequalities action needed within BSW and was disseminated with the LDA Programme Board members for noting.

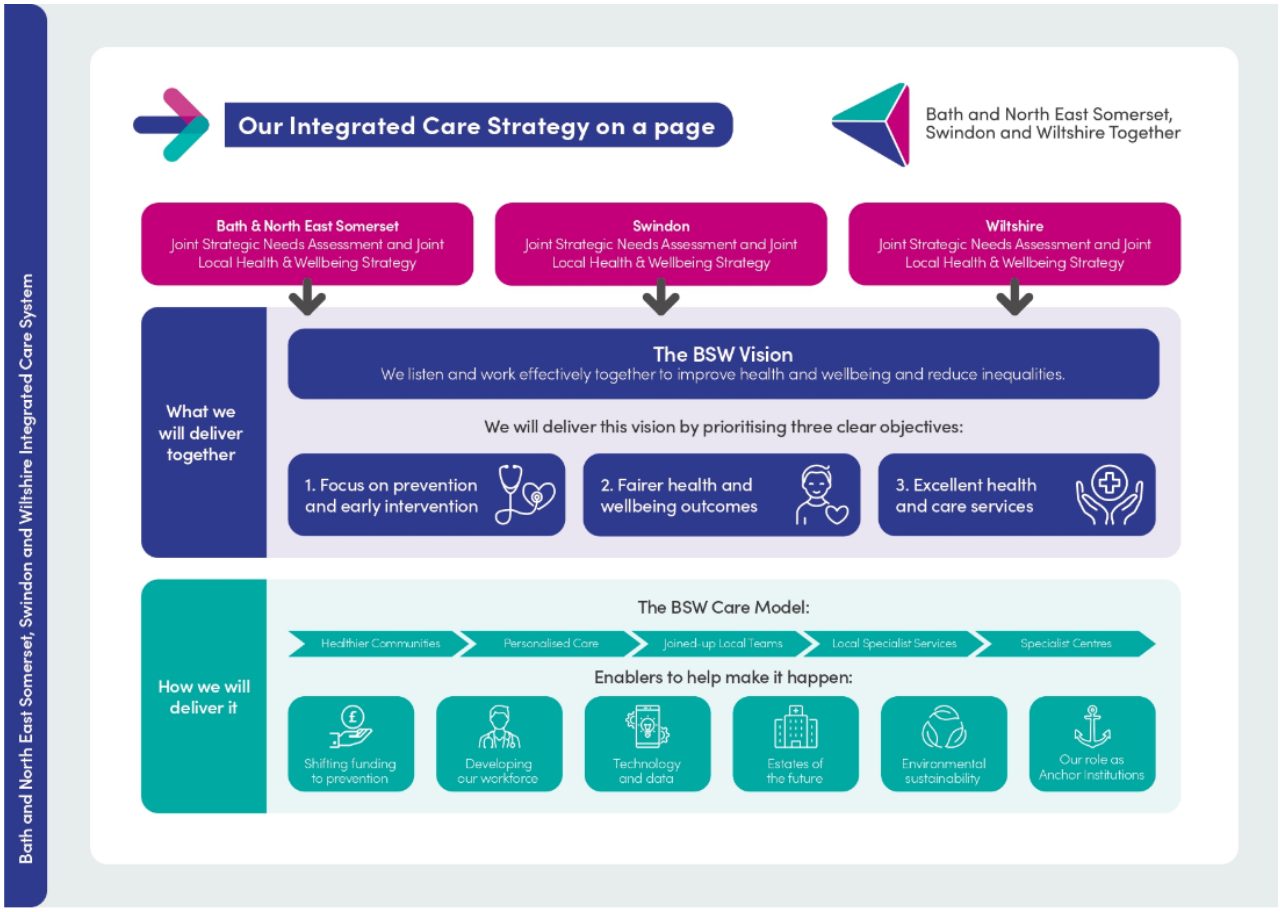
The EQIA as expected, again identified key areas of inequality aligned to the national LeDeR programme which are:

- Age (premature/avoidable mortality risks).
- Race (minority ethnic group LeDeR reviews are low nationally and in BSW); Healthwatch to support future co-production and engagement.
- Disability (by definition and scope of LeDeR, all LD and ASD reviews must have a documented diagnosis).

A BSW data summary aligned to the protected characteristics is in section 7 of this report.

2.5 BSW LeDeR and System Inequality Progress: Integrated Care Partnership (ICP)

The BSW LeDeR programme will work with the ICP in 2023-24; to ensure that the LeDeR actions are aligned and progressed as a system through the new BSW strategy vision delivery and targeted pillars of work as agreed via LDA Programme Board.



A link to the full Strategy is: [Integrated-Care-Strategy-v4.pdf (bswtogether.org.uk)]

2.6 South West LDA Programme-Health Inequalities and Improvement Group

BSW are also active members of the South West (SW) LDA Programme-Health Inequalities and Improvement Group, which was established to focus on the known health inequalities across the SW and nationally.

Key priorities agreed at the start include:

- Triangulation of findings and ambitions around health equality across NHSE; quarterly meetings in place with a focus on understanding and pushing forward the agenda for improving health (regional network of leaders and managers involved in health equality including safeguarding and broader health equalities).
- Link with Southwest (SW) LD and autism health equality programme
- Link with the SW GP Network as a mechanism to raise awareness of LD and autism in Primary Care
- Focused work to be conducted by the southwest equalities programme to understand the Mental Capacity Act and DNACPR, pneumonia and all associated issues, cardiac conditions, and cancer/screening.

- To ensure that lived experience people are at the centre of the health and equality program
- Increase Annual health checks for people with an LD (designed to review the health of people on a practice LD register) ensuring that coding's are correct within GP practices.
- Constipation project for adults with a learning disability and autism; plans to pull together a constipation pathway, review individualized bowel care plans and work toward a SW awareness campaign.
- Flu and COVID vaccination programmes
- Health and Wellbeing Network with the regional adjustment digital flag

3. LeDeR National Roles and Responsibilities: LeDeR 2021 Policy

3.1 NHS England (NHSE): National and South West

NHSE funds, manages, and monitors compliance within the (non-mandated) LeDeR programme. The NHSE South West LeDeR team now share quarterly LeDeR compliance data which is also shared with the SRO.

3.2 Reporting Requirements: ICB's are requested to provide quarterly highlight updates to the Regional Coordinator who then writes a South West combined progress report to share with the national LeDeR team.

3.3 There is a South West LeDeR operational group of which the LeDeR LAC's are members and contribute to operational discussions.

3.4 LeDeR National IT Platform

The Bristol University contract commissioned previously to supply the national LEDER Platform and system ended on 31 May 2021 (and was initially commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England).

NHS commissioned the South, Centre, and West Commissioning Support Unit (SCW) to deliver the LeDeR platform, which went live on 1 June 2021, and has remained under continual development since. The platform has generated ongoing system operability issues since its launch, and these continuing concerns have been raised at the South West LeDeR (Local Area Contact) Operational Meetings.

4. BSW LeDeR Programme Statement of Purpose

4.1 Extracted from the BSW LeDeR Strategy 2021-24:

BSW set out a continued commitment to the non-mandated LeDeR programme and updated 2021 national LeDeR policy; to ensure that service improvement arises following the learning from reviews of the deaths of people with a learning disability and autism both nationally and locally.

The BSW three-year strategy reframed the plans and objectives that were already written in the BSW 2020 annual LeDeR report, and also agreed with providers across the system during a previous BSW LeDeR workshop.

Whole system engagement and communication of the BSW LeDeR programme remains a focus to:

- Ensure that people know how to report a death to LeDeR by understand the benefits and outcomes.
- Continued recruitment of LeDeR reviewers and a senior reviewer.
- Ensure system ownership, learning and action delivery as the ICB and ICS matures.

5. BSW LeDeR Programme Governance Arrangements

5.1 The BSW LeDeR Governance and Assurance Group (previously called a Steering Group in the old national policy) is tasked with the remit to ensure that learning and recommendations are rolled out and embedded from the learning of local BSW and national LeDeR reviews. Members of the group include expert representation from the BSW acute hospitals, mental health and local authorities, as well as Healthwatch to represent the public.

5.2 Assurance and approval of all LeDeR progress and annual reports continues via the BSW Quality and Outcomes Assurance Committee (QOAC) and BSW LDA Programme Board.

5.3 LeDeR reports into the BSW Learning Disability and Autism Programme Board with LeDeR aligned directly to the four workstream pillars:

Workstream	Responsibilities	Principles in which Workstreams will work to:
People, their families and their support	• Housing • Respite • Specialist assessments • LDA Key worker programme • Care Co-ordination	• Learning from Cawston Park • Learning from each other and EBE • LeDeR • Training • Addressing Health Inequalities - EDI
LDA/ND Pathways	• Wellbeing • Annual Health Checks • Community Provision – Provider Market • Physical Health including Vaccination, screening. • People with forensic support needs • Neurodevelopmental Pathway including ASD and ADHD • LeDeR link	
Acute Care Pathway, Prevention and Oversight (ACOP)	• Case escalation • DSR reviews • MADE events • Hospital Discharge • Reduction in OOA placements & oversight • Quality Assurance • Delivery of financial efficiency (placements and S117)	
North LDA Capital Delivery Group	• Delivery of the LDA North Capital Programme	

5.4 BSW LeDeR Executive Leadership

The BSW ICB Chief Nurse Officer is the Executive Lead for LeDeR. The Deputy Director of Nursing and Quality continues in leading the oversight of the BSW LeDeR programme.

5.5 BSW LeDeR Resource Capacity Update

The LeDeR Local Area Coordinator (LAC) role manages the allocation, timeframes for submission, approval, and reporting on all LeDeR reviews, along with a BSW LeDeR coordinator who works two days a week.

BSW still require a substantive team of reviewers to align with the national 2021 LeDeR policy. BSW CCG continue to use ring fenced national LeDeR funding to source quality assured agency reviewers. Options appraisal papers have previously been drafted for executive review and system progression; to secure dedicated system reviewers whilst noting that there is a national mandate to make large savings in all ICB's, which will affect access to dedicated resource for a non-mandated programme.

5.6 LeDeR Legal Basis To Access Health and Care Records

A key part of the Learning Disability Mortality Review (LeDeR) programme is to support local areas to review the deaths of people with learning disabilities. As part of this process, it is important for local reviewers to access the deceased person's health or care records, and this is nationally agreed for LeDeR. The LeDeR web platform states that section 251 of the NHS Act 2006 is the legal basis for LeDeR information sharing: https://leder.nhs.uk/your-personal-information

Health records relating to deceased people do not carry a common law duty of confidentiality, but it is Department of Health and General Medical Council (GMC) policy that records relating to deceased people should be treated with the same level of confidentiality as those relating to living people. However, whilst confidentiality is an important duty, it is not absolute.

Professionals can disclose personal information if:

- The patient consents. This is not applicable in the LeDeR programme as the person who is the subject of the review will have died without giving consent.

- It is required by law. This is not applicable in the LeDeR programme as there is no legal mandate for confidential patient-identifiable information to be shared for use by the programme.

- It is allowed by law. Some legislation falls short of creating a duty to share confidential information; instead, it makes it possible for organisations to share confidential information. Such confidential information sharing must be necessary and proportionate to the purpose. Section 251 of the NHS Act 2006 provides the Secretary of State for Health with the authority to make regulations that set aside legal obligations of confidentiality to allow the disclosure of confidential patient information in situations where it is not possible to use anonymised information and where seeking consent is not practical. Further information about Section 251 can be found by following the link: http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/.

Noting the ongoing delays in the sharing patient and client records requests, the ambition remains for future BSW reviewers to have SMART card/IT access to improve access to GP and system records. This will be progressed if and when a BSW dedicated and substantive reviewer team is in place.

5.7 Integrated Care System Ownership

The 2021 LeDeR policy makes it clear that the governance oversight within the ICS rests with an agreed executive lead, and that ICS's must ensure that LeDeR is an integral part of ICS governance and quality reporting arrangements:

> *'Local governance arrangements should feed into local quality surveillance groups and, for local authorities, health, and wellbeing boards, to ensure the people who can affect the necessary improvements understand the issues that need to be addressed. Collaborations between partners across health, care services, public health and the community and voluntary sector will be key to help to address health inequalities, improve outcomes and deliver joined up, efficient services for people with a learning disability and autistic people'*

And:

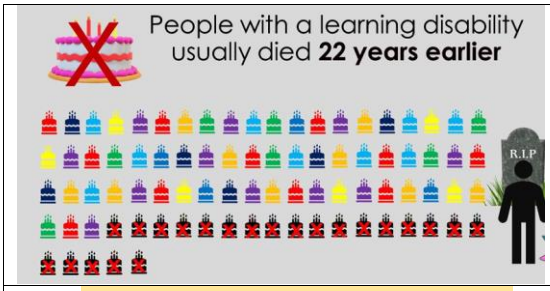
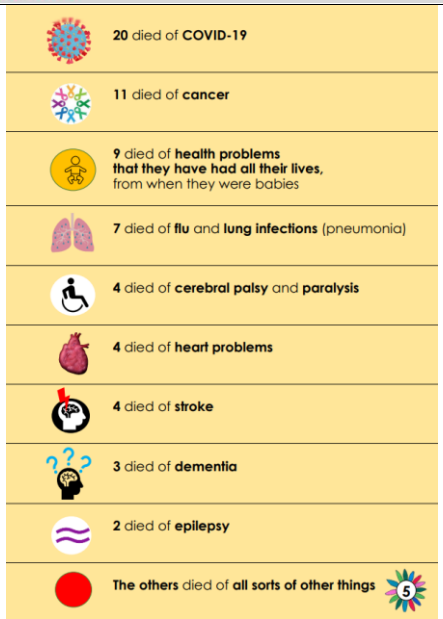
> *Local authorities are expected to contribute to and be part of ICSs and have a role to play in reducing health inequalities and premature mortality of people with a learning disability and autistic people. Local governance arrangements must promote meaningful co-production with people with lived experience.'*

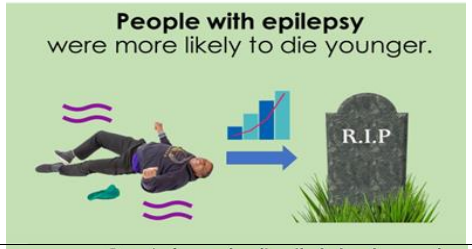
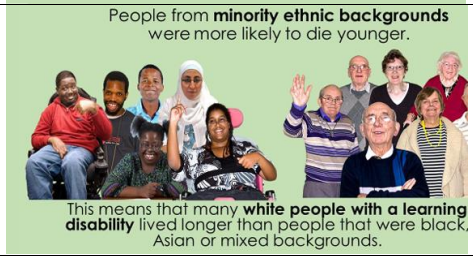
The BSW LeDeR SRO and LAC will ensure that LeDeR is embedded in all ICB and Integrated Care Partnership (ICP) strategy and associated implementation plan during and beyond the next financial year.

6. The National LeDeR 2021-22 Annual Easy Read Report Headlines

The following information is extracted to demonstrate a high level summary of the last national LeDeR report findings.

LeDeR 2021
Learning from Lives and Deaths – People with a Learning Disability and Autistic People

	**People with a learning disability died 22 years earlier than the rest of the population**
	**Causes of death (of each 100 people who had died) showed that the top causes of death were:** • **Covid** • **Cancer** • **Lifelong health problems** • **Flu and lung infections** • **Cardiovascular issues** • **Dementia**

	**Covid vaccinations worked by reducing the risk of people dying before they should**
	**Good care included :** • **annual health checks** • **learning disability liaison nurses**
	**Problems were:** • **Carers not recognising that people were ill** • **staff didn't make reasonable adjustments**
	**People with epilepsy died younger**
	**People who were not white died younger**

Bath and North East Somerset, Swindon and Wiltshire
Integrated Care Board

> *"People with a learning disability have a significantly lower life expectancy than the general public. If this is to change, it's vital that we review these deaths so that we can learn from them, and to ensure that best practice is followed wherever possible. Although we found fewer problems in care compared to previous years, there are areas where things can be improved, with 8% of avoidable deaths being linked to cancer, 14% to hypertension, and 17% to diabetes as well as to respiratory conditions"*
>
> – Professor Andre Strydom, the report's Chief Investigator and a Professor in Intellectual Disabilities at King's IoPPN

Easy Read Report : https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-2021-easy-read-report.pdf

Full Report: https://www.england.nhs.uk/wp-content/uploads/2021/06/LeDeR-Action-from-learning-report-202021.pdf

7. 2021-22 BSW LeDeR Deaths: Local Analysis

7.1 BSW Data

This part of the report is created using only local quantitative data and qualitative intelligence, as national data breakdown is not yet available but is expected in 2023.

7.2 BSW Quality of Information and Information Sharing Delays

Delays in receiving requested health and social care records sharing has delayed the completion of some reviews, affecting BSW compliance in year. Delays in Structured Judgement Reviews have also been a theme in 22-23. Escalation has occurred in each case.

7.3 LeDeR Notifications Caveat

LeDeR remains notification of death dependant, to enable a LeDeR review to take place. As the programme remains non-mandated, the number of LeDeR death reviews in BSW are not validated or referenced with the total number of LD now ASD deaths. Additionally, the accuracy of demographic information and LD/ASD diagnosis is a noted action requiring improvement locally in BSW and nationally. BSW have been increasing the LeDeR programme campaign communication; to improve notification numbers. BSW have updated and shared a reviewer quality checklist which is improving the completion of all demographic information when available.

There have been minimal autism notifications in BSW and in the South West despite promotion of the policy change last year to include autism, with notification for BSW autism reviews only being sadly out of scope on review commencement.

7.4 Child Deaths Caveat

Child deaths aged 4 years + are in scope in LeDeR, however, rather than being subject to a full LeDeR review, child deaths are reviewed, and lessons are learnt by local Child Death Overview Panel processes (CDOP) with input from a LeDeR reviewer or LAC when invited.

LeDeR LACs are sent and upload the completed CDOP review form and add key learning within the review template, with no other LeDeR process required. The BSW LAC has sought invitation to CDOP panels to support learning and LeDeR intelligence.

The BSW LAC suggested that the associated Bristol CDOP team include the link with LeDeR in their 2021-22 annual report previously to ensure alignment.

The child death numbers are also very low, so this report therefore refers only to adult deaths.

For further CDOP information please follow the link:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/859302/child-death-review-statutory-and-operational-guidance-england.pdf

7.5 BSW Data Presentation

The following data relates to learning disability deaths only by notifications and reviews during the reporting period. Due to low numbers of less than 5 in some areas data is presented as a percentage or excluded to protect confidentiality.

7.6 BSW LD Population Data

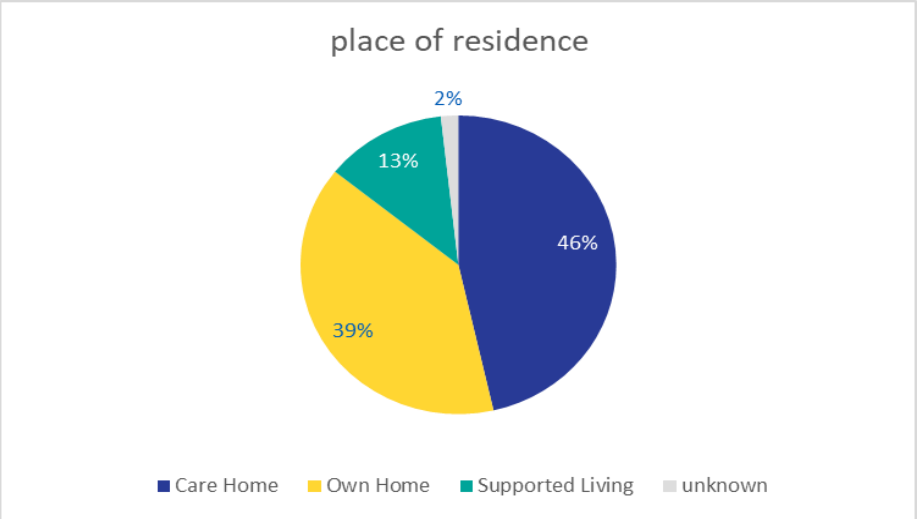
The number of people recorded on the BSW GP LD registers which has increased by 169 people when compared to last year's GP LD register data, which positively demonstrates raised awareness:

	LD Register
BaNES	1,107
Swindon	1,233
Wiltshire	2,472
BSW	4,812

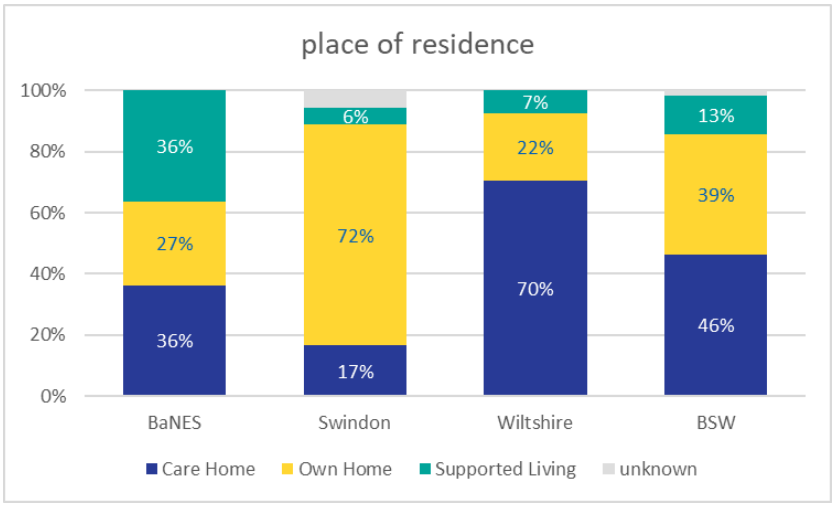
There are more men than women currently on the BSW GP learning disability registers.

7.7 Usual Place of Residence

The place of residence has been captured to identify where people lived prior to death in BSW. The BSW majority were living in commissioned care provision:



More people lived in their own home in Swindon however, whilst the majority in Wiltshire lived in a care home, which will be shared for locality LDA leads review and intelligence:



7.8 BSW LeDeR Notifications

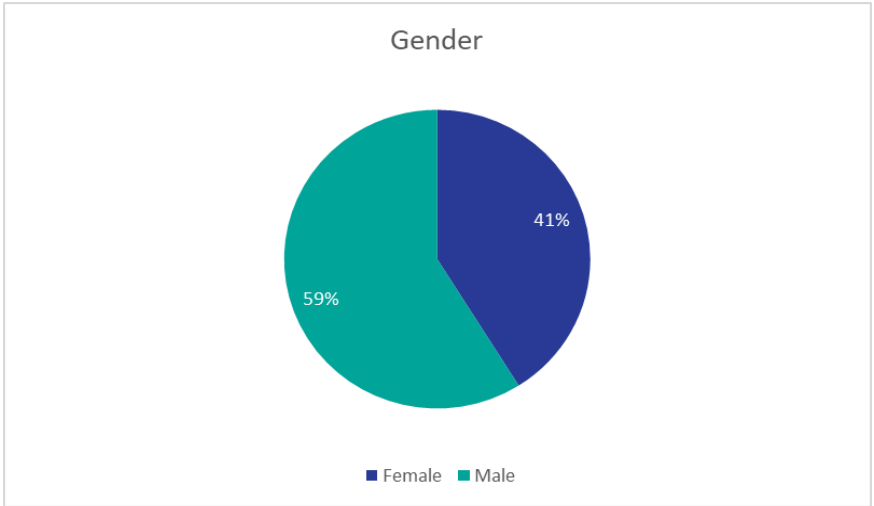
A total of 56 BSW LeDeR death notifications were received in the reporting period 01/04/22-31/03/23 compared to 49 last reporting year so assumption can be made that this has increased due to the ongoing promotion of LeDeR (see 7.3 for caveat that notifications are not mandated and that the numbers are relatively small compared to the rest of the population).

The most (8) deaths notified to BSW LeDeR occurred in October 2022, but no trend was noted as the bulk of notifications came from the central LeDeR team.

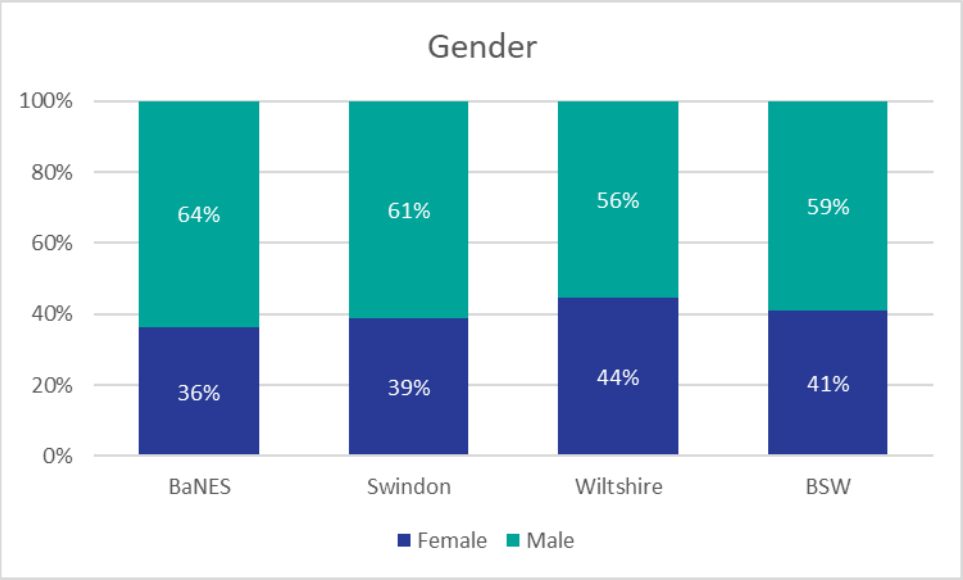
The lenth of time from death to LeDeR notification varied during the year. Some deaths were notified retrospectively following indentification.

7.9 Gender

There has been more male than female deaths reported into BSW LeDeR during this year, which also aligns to the fact that there are more men on the GP registers, so reflective of the current learning disability GP register data.



The following graph shows the gender breakdown per locality:

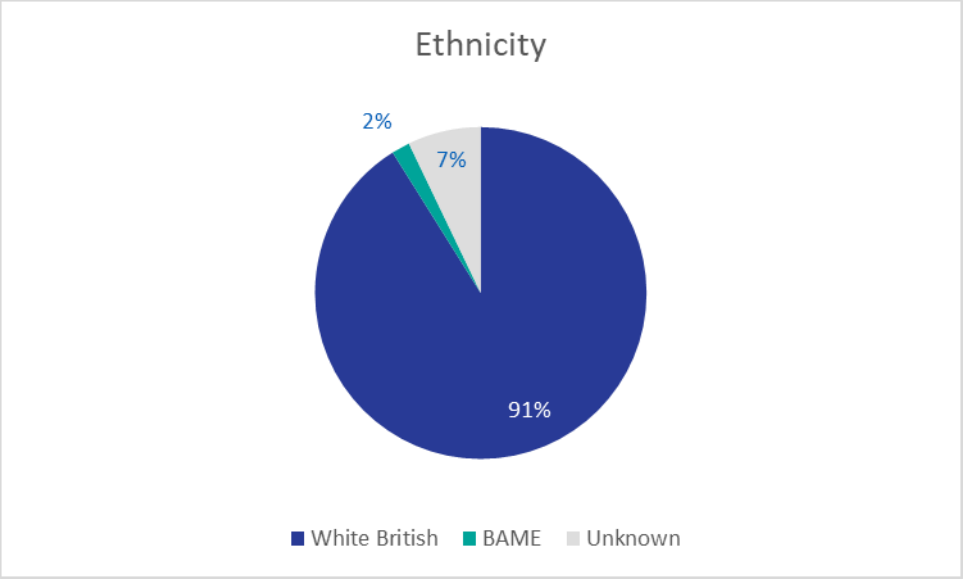


7.10 Race/Ethnicity

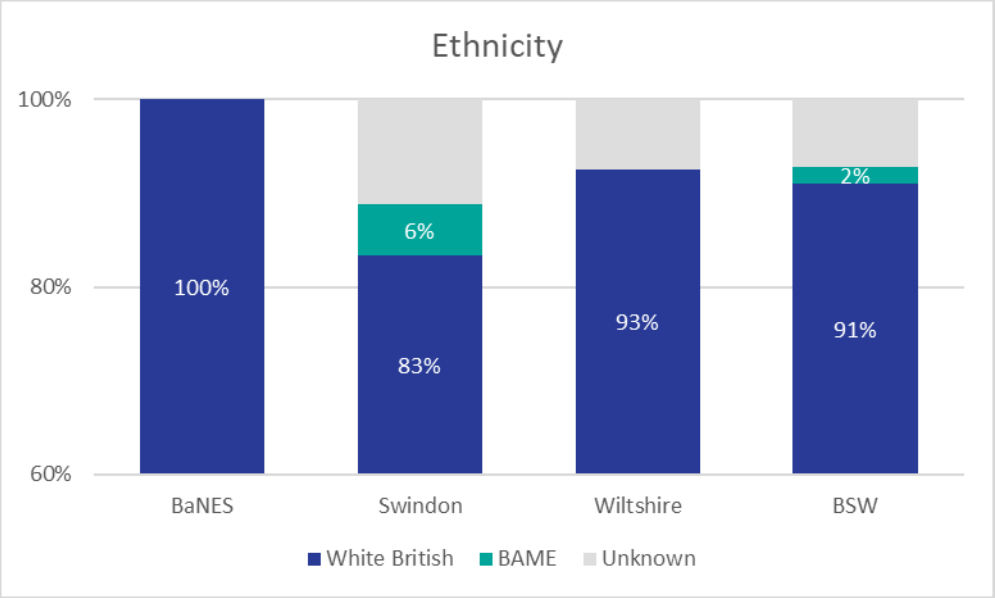
The information for ethnicity is taken directly from LeDeR notifications.

The following tables show that most notifications are white British or left blank (notification gaps are from the notifier, so outside of BSW LeDeR control).

As per EQIA and national learning, the number of minority ethnic review notifications remain very low despite BSW in year campaigning.



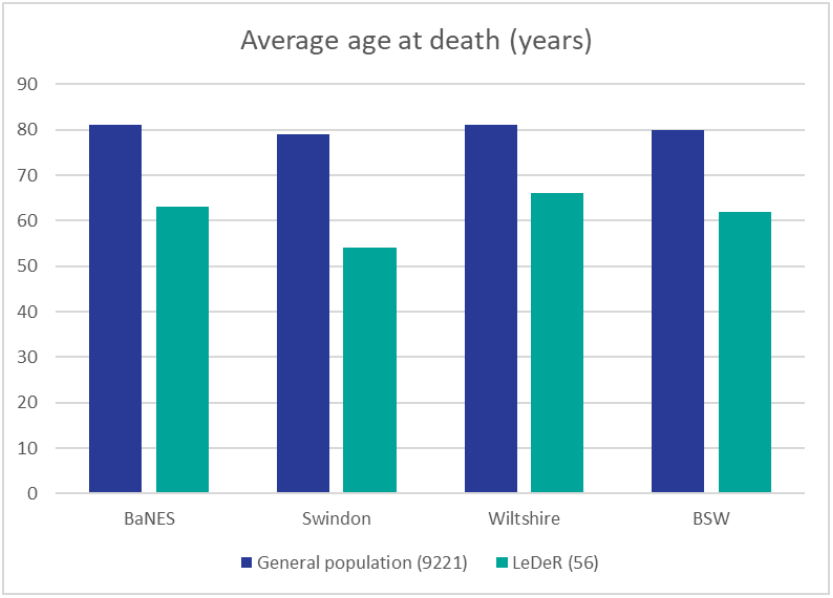
Locality Ethnicity-This shows Swindon reporting and aligns to the diverse ethnicity in that locality:



7.11 Average age at death

The average age at death in BSW LeDeR deaths during the year are compared to the rest of the population per locality and demonstrates premature deaths (averaging at 20 years younger as per national data) in comparison.

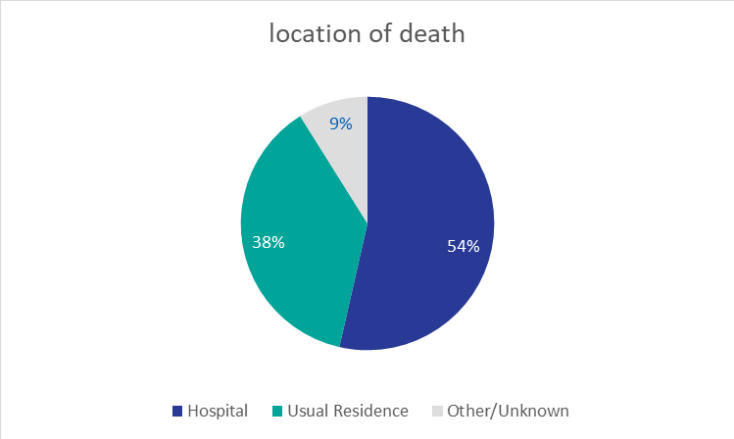
Swindon showing a slightly lower age at death when compared to BaNES and Wiltshire which will be further scrutinised in 2023-24 :



7.12 Location of Deaths in BSW Reviews

Data is extracted again from notifications made into LeDer hence 'other' and 'blank' data gaps that are outside of BSW LeDeR control.

Most deaths have occurred in hospital and further work continues to improve the earlier idenitification and treatment of deteriorating conditions and the identification and personalised choice in end of life planning (preferred place of care and death):



7.13 Reporters of Deaths in BSW

Health providers have previously made the majority of notifications to LeDeR.

During 2022-23 a BSW LeDeR communication drive was undertaken (as per 20-21 report) to improve notifications made across the health and care system. The following table demonstrates that this has increased awareness and notifications (those marked with ** symbols have made less than 5 notifications):

reporter of death organisation		total
hospital	RUH	11
	GWH	7
	AWP	**
	Salisbury NHS Trust	**
	University Hospital Bristol	**
Local Authority	Swindon Borough Council	9
	Wiltshire Council	7
	Hampshire County Council	**
other	Wiltshire Health & Care	**
	White Horse Care Trust	**
	Choice Care Group	**
	HCRG Care Group	**
	Voyage Care	**
	Medvivo/NHS111	**
	Dimensions UK	**
	Courtyard Surgery	**

** less than 5

7.14 Performance against the national target

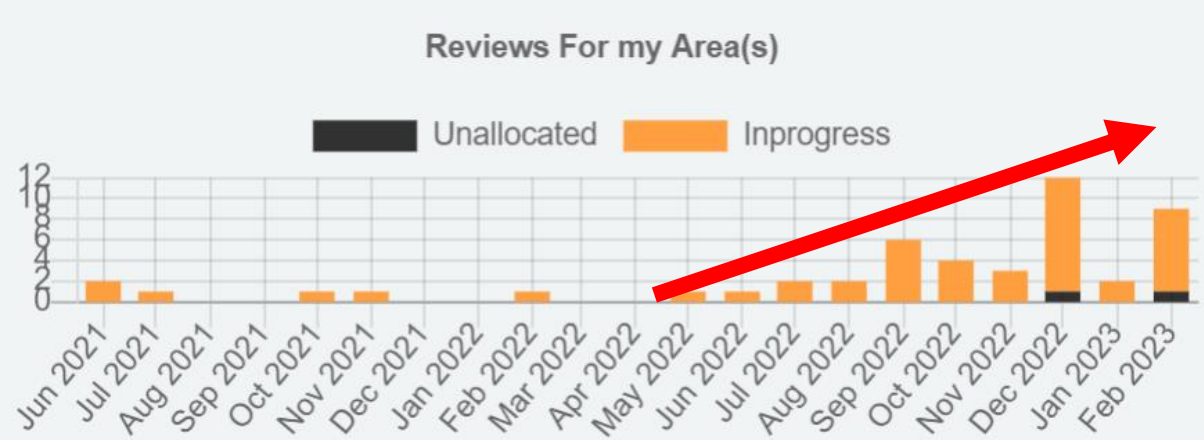
BSW allocate all new reviews within seven days (see 'Reviews for my Area' graph below for assurance).

National and BSW data demonstrates that the target key line of enquiry (KLOE) has not been met in 22-23 (to consistently complete all LeDeR reviews within 6 months of notification to LeDeR) due to:

- the low number of BSW (agency) reviewers with finite capacity
- complex cases
- some unavoidable delays in statutory processes such as safeguarding enquiries and also hospital Structured Judgment Reviews (SJR's) which were escalated and reported into the BSW LeDeR Governance and Assurance Group in March 2023.

Specifically, the three BSW agency reviewers could not keep pace with the number of reviews that were received in bulk (particularly in December 2021 and February 2022) along with the complexity of some reviews. Two additional experienced agency reviewers have been source in mitigation, whilst the focus for 2023-24 will be the required BSW in-house reviewer team and BSW LeDeR community of practice group proposal.

The following table was a February 2023 point in time/dynamic graph from the LeDeR portal, which shows the increase in reviews during 2022-2023 (note-the graph is not wholly accurate as 'unallocated' is incorrect, as the portal takes time to remove the two cases that were out of scope for a LeDeR review) :



7.15 Causes of BSW LeDeR (LD only) Deaths in 2022-23

BSW LeDeR cause of death data has such a wide variety of causes that data representation requires qualitative and quantitative information to draw a rounded conclusion.

Some of the 'in year' reviews continue into 2023 so the cause of all deaths is not yet known.

The following table captures the BSW causes of death in comparison to the general population for comparison:

- The left LeDeR table represents the causes of death as documented in the BSW LeDeR reviews.
- The table on the right shows the general population causes of death in BSW during the same period.
- Manual review of the BSW LeDeR qualitative information in year also highlights that early onset dementia features thematically but is not directly captured in the cause of death.

LeDeR cause of death	General Population cause of death
not known	Unspecified dementia
pneumonia/chest infection	Chronic ischaemic heart disease, unspecified
covid	Malignant neoplasm: Bronchus or lung, unspecified
cancer	Alzheimer disease, unspecified
cardiac	COVID-19
Aspiration Pneumonia	Other specified general symptoms and signs
sepsis	Acute myocardial infarction, unspecified
stroke	Pneumonia, unspecified
other	Malignant neoplasm of prostate
	Malignant neoplasm: Breast, unspecified

7.16 BSW Reviews-Qualitative Stories

Individual LeDeR review details are not shared in this report due to confidentiality. Thematic learning is noted by the team.

7.17 Benchmarking

BSW will be able to review and benchmark once:

- All ICB's have published annual reports
- the national LeDeR report is published in the autumn.

8 BSW LeDeR and ICS Collective Quality Improvement Progress

8.1 BSW LeDeR Panel: Quality of Reviews

A previous BSW LeDeR governance and quality improvement review instigated a Quality Assurance (QA) Panel for the members to have oversight assurance of all reviews and to challenge any gaps in information or concerns, which is documented through the confidential BSW QA Panel notes. Members are experts from BSW providers who challenge and approve reviews collectively.

The BSW Quality Assurance (QA) Panel receive case learning summaries under the Panel review process to ensure robust case learning is shared (and improvements are recognised as required by members to share the learning in each locality). The panel also focus on the lives and wellbeing of people to seek learning and action required.

A BSW checklist was developed and shared with reviewers; to improve the quality and detail of reviews post the national 2021 policy implementation (which saw the LeDeR review template cut significantly with an identified potential risk of key information being missed). The BSW Local Area Contact (LAC) amended this checklist during 2022-23 in response to a few quality concerns. The updated checklist was shared with all reviewers and is now required to accompany all completed reviews for assurance that BSW expectations are met.

There is an NHSE expectation to convert more (initial) LeDeR reviews into (in-depth) focused reviews. The South West LAC's group have discussed that local quality checklists (seeking more assurance beyond the initial review constraints) may have inadvertently affected the focused review numbers.

A live QA Panel action tracker is in place to monitor action delivery.

8.2 Improving Annual LD Health Checks (AHC's)

The national target is for 75% of people (aged 14 years+) on the GP Register to receive an AHC by March 2024.

People can and do decline to attend AHC's, but work is undertaken to improve understanding and reassurance that they are a positive thing to do, using reasonable adjustments such as easy read. Data for those declining requires review in 2023-24.

Annual health checks are important as they provide dedicated time with a GP or nurse to:

- Help people to get to know their GP better
- Check the health of people and how they are managing any existing health conditions

- Identify new health problems early to reduce the risk of premature/avoidable deaths
- Check that vaccinations are up to date
- Encourage cancer screening uptake
- Ensure a medication review is completed
- Provide a health action plan so that people and their carers can make changes to improve health

The BSW LDA Board monitor the progress in primary care to deliver annual health checks (AHC) for people with a diagnosis of learning disability aged over 14 years.

BSW LeDeR team have worked with the GP Clinical Lead to continually raise awareness and the uptake of AHC's.

8.3 BSW AHC Data 

BSW end of March 2023 'interim' local data demonstrates improvement in year (late data will potentially improve the final numbers too):

- A seasonal trend continues, with most AHC's being completed in the last two quarters of the year.
- The interim total of BSW AHC's is 3,468.
- This equated to 465 more AHC's in 2022-23.
- 72.1% of AHC's were completed compared to 61.8% in 2021-22 across BSW, almost meeting the 75% target this year.
- 96% of people also received a health action plan

Opportunities are noted within the data to:

- increase uptake in people aged under 35 years, particularly in the 14-18 age bracket
- increase the number of men attending AHC's
- increase AHC's for people living in more deprived areas

8.4 BSW Vaccination Programme

Vaccination is a preventative measure to produce immunity against known disease. This is a priority for people with a learning disability, as LeDeR learning continually demonstrates deaths from pneumonia (caused by bacterial or viral infection) and aspiration pneumonia (inhalation of oropharyngeal contents into the lower airways that leads to a chemical pneumonitis, lung injury, and resultant bacterial infection; commonly occurring in patients with risk factors such as impaired conscious level, swallowing dysfunction, and gastrointestinal disease).

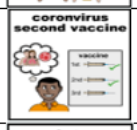
8.5 BSW Vaccination Reasonable Adjustments: ✓

All (now closed) BSW Covid/Flu vaccination sites offered reasonable adjustments such as:

- Fast track to avoid queues.
- Vaccination in a quiet/separate space/outside the vaccination centre if suitable.
- Pre-visit to familiarise and ask questions even if not being vaccinated.

In addition, there were specific BSW outreach clinics for LD services, with a Swindon clinic arranged by the BSW Lead GP, an easy read letter written by the BSW LAC as an example:

Covid and Flu Injections for People with a Learning Disability

	it is important that you keep safe and well this winter
	there are Covid and Flu vaccinations available
	Tuesday 29th November from 8.30am and 5.30pm you do not need to make an appointment
	at The STEAM Museum, Swindon where you can park outside Fire Fly Avenue, Swindon SN2 2EY
	there is help and information available if you need
	bring your health/hospital passport so we know how to help you

Specific needs requests by people are managed by the BSW Patient Advice and Liaison (PALS) team on the patients behalf as requested and required.

8.6 Covid Vaccination: Learning Disability Uptake ✓

The national 2021 annual report clearly demonstrated that Covid vaccination reduced the risk of death nine fold. BSW have actively and creatively worked to increase uptake. Most reassuringly, the BSW GP learning disability register Covid vaccination data for 2022-23 is very high for first and second doses, with opportunity to improve booster uptake noted:

- 1st Dose 91.8%
- 2nd Dose 89.8%
- Booster uptake 68.3%

The BSW data intelligence team do not currently have access to the South West and national data to compare uptake.

8.7 Flu Vaccination

There is opportunity to dramatically increase flu vaccination in 2023-24 on reviewing the interim 2022-23 data when comparing the overall learning disability uptake. The data is not included within this report however, as the author has not received approval to share at the time of writing. Improving flu vaccination is an action for 2023-24.

8.8 South West Learning Disability Collaborative and Social Care 

BSW is part of 300 members of the West of England Academic Health Science Network (WEAHSN) LD collaborative, which was established in 2019 to focus key actions required. The collaborative has over time developed 'quick guide' videos alongside delivering regular webinars and information to improve access to care and support.

Social care providers have been specifically directed by the BSW LAC to access and use the training resources in RESTORE2 to increase earlier deterioration recognition and onward reporting. BSW will continue sharing the link to training and information. This action has also been shared (along with dysphagia training gaps) with the BSW ICB Aging Well team to share learning opportunities. Links are:

Henry's story: using RESTORE2 to support care home residents with learning disabilities - West of England Academic Health Science Network (weahsn.net)

Training and resources for care providers including RESTORE2 - West of England Academic Health Science Network (weahsn.net)

The Learning Disabilities Collaborative | West of England AHSN (weahsn.net)

8.9 BSW Academy 

The developing ICB Academy provides system opportunity to share LeDeR learning directly; to shape system future education and mandatory training. Early conversations were held in March 2021 and a LeDeR learning summary paper was submitted to the academy in 2022 to share LeDeR learning for system action (see appendix E for the full paper).

The BSW LeDeR LAC is subsequently a member of the Oliver McGowan training task and finish group, but there is no scope to amend the training script, so BSW LeDeR awareness campaigning continues in parallel.

8.10 South West (SW) LeDeR Operational Group: System Learning

The BSW LeDeR LAC and Coordinator will continue to learn and share with the SW LeDeR LAC's and continue to work on joint projects such as dysphagia, cancer screening and obesity.

8.11 BSW LeDeR Members Feedback

BSW LeDeR Governance Group members and BSW reviewers were invited to share provider action and their voices into this report. Please see Appendix D for their narratives.

8.12 BSW LeDeR Learning Events

A LeDeR specific annual report learning event was held on the 19th of July 2022; to share the BSW and national annual LeDeR reports learning. This has been followed up by another event in December 2022 with social care as the target audience following the BSW LAC social care 'Call to Action' request.

The BSW LAC has also presented at numerous health and social care team meetings, forums, care home managers and delivered bespoke GP Champion (LeDeR awareness) in some GP practices; to share the LeDeR learning and increase system engagement. Improving links with safeguarding teams in BSW also continues, to align statutory safeguarding (section 42) enquiries with LeDeR reviews information.

The BSW Lead GP and LeDeR LAC have worked collaboratively throughout 2022-23, and thanks is expressed to Dr Molly Moffat for her support.

8.13 BSW LeDeR and Learning Disability Blogs

A BSW LeDeR LAC blog was written following presentation at the BSW End of Life Alliance and is online to promote LeDeR inequalities within the system end of life discussion: https://www.partoflife.org/blog/end-of-life-care-and-learning-disabilities

Dr Molly Moffat BSW Clinical Lead for Learning Disabilities and Autism blog: https://bswtogether.org.uk/blog/triangle/ensuring-those-with-learning-disabilities-and-autism-have-access-to-vaccines/

8.14 Aspiration Pneumonia

BSW held a priority action Task and Finish Group meeting to carry out a system pathway review with speech and language therapy expertise; to tactically review commissioned care and support and identify areas of improvement. This group discovered that dysphagia training is not mandated, with assumptions that not all care providers know how to recognise swallow issue and how to report and manage them. Collaborative work

now progresses in the South West and a resulting dysphagia knowledge and skills workbook is under final review before sharing.

8.15 Hospital/Health/Care Passport 

BSW held a priority action Task and Finish Group meeting to carry out a system pathway review following extensive research. BSW consensus was reached to approve any provider passport template used, whilst signposting to the Mencap and National Autistic Society passport templates if asked. System auditing of passport use will be a 2023-24 action to continue the quality improvement cycle of progress.

8.16 Primary Care and LeDeR Learning 

Dedicated GP Networks (GPN) funding was secured later in 2021 to provide LeDeR specific training to GPN's. The project has continued in 2022-23 to upskill practices in improving the quality and access to care to meet the needs of people. A bespoke and dedicated event is to be held in May 2023 (which was postponed from January 2023 due to system pressures) to share a parent carer story, share the LeDeR learning to increase preventative annual health checks, vaccinations and cancer screening. Wider provider and social care invitation has been shared to maximise the impact.

8.17 Service User Representation 

Healthwatch are members of the BSW Quality and Assurance Group with the remit to represent and improve coproduction for all service users, including those of minority ethnic origin.

Further LeDeR work is planned in 2023-24 to engage with specific ethnic community groups to understand the barriers and issues to diagnosis and support.

The BSW LAC has also met service users and shared learning about vaccination and AHC's in BSW, as well as being a member of the South West User Voice Group.

9. BSW 2023-24 Proposed Priority Actions

9.1 BSW LeDeR Team

The 2023-24 the main BSW LeDeR team governance priorities will include:

- increasing BSW capacity to ensure that reviews are completed within the KLOE
- the securing of a dedicated in-house reviewer team
- continuing to provide system LeDeR learning and reporting to the LDA Programme Board and sub Steering Groups, ICB Quality Assurance and Outcomes Committee, Safeguarding Partnership Boards, Public Health and population health transformation workstreams; to ensure system action oversight, delivery, accountability, and leadership
- Deliver the ReSPECT South West LeDeR audit quality improvement plan
- Develop a draft 2024-28 BSW LeDeR Strategy for ICS approval/action

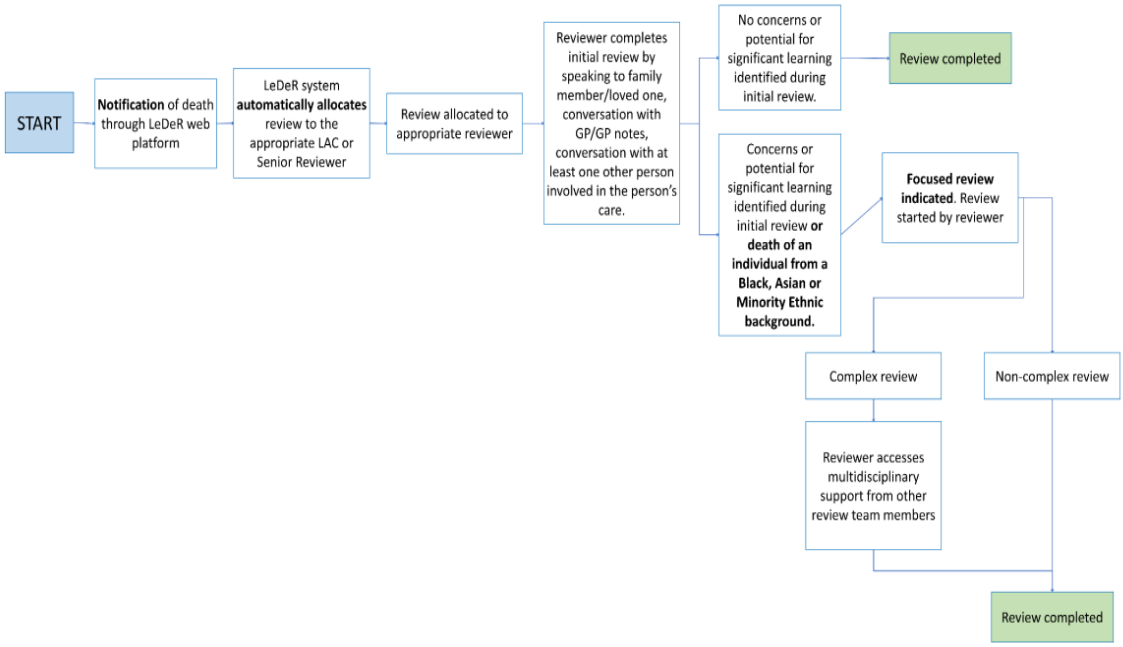
9.2 2023-24 BSW LeDeR Learning and Action Proposed Priorities

BSW LeDeR has identified further system opportunities to:

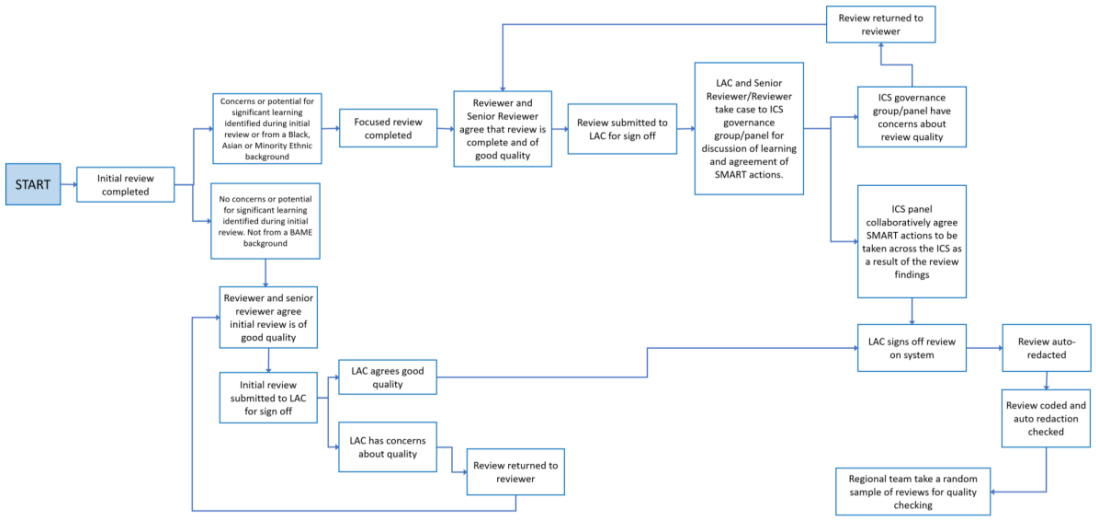
- Continue a BSW population prevalence data analysis: particularly to review the number of minority ethnic LeDeR notifications verses latest population mortality data
- Develop an Easy Read and patient information library across the BSW system; to support providers to make reasonable adjustments and an ICB webspace has been requested previously and remains awaited
- Increase ICB/ICS system flags; to alert all providers to the reasonable adjustment needs of service users
- Ensure locality specific learning briefings and the sharing of case learning with BSW providers by the BSW LeDeR governance group members
- Propose to audit the BSW Health/Hospital Passport process; to increase the use to ensure that reasonable adjustments are made to meet people's needs (also considering digital options too)
- Continue to improve access and quality of annual health checks to help people (and their carers or family) in identifying and managing their health needs and improving healthier lifestyles
- Supplement the upcoming Oliver McGowan mandatory to improve awareness and action from BSW specific LeDeR learning
- Improve all routine cancer screening attendance and health education support using the new LeDeR Cancer Screening funding
- Improve Mental Capacity Act (MCA) adherence; supporting people to make their own choices or lawfully acting in the best interests of poeple
- Improve advanced care planning and choices with the BSW End of Life Alliance; reducing deaths in hospital as the 'expected' option

(See Appendix C for BSW LeDeR thematic Easy Read Learning Poster)

Appendix A:
The 2021 LeDeR National Policy- Review Process



The 2021 LeDeR National Policy-Quality Process



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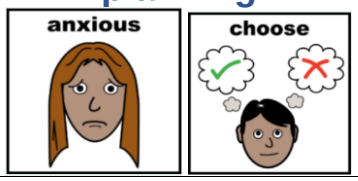
Appendix B: BSW LeDeR Poster

Reasonable Adjustments: BSW Guide to Supporting People with a Learning Disability and/or Autism

BSW LeDeR Learning	Reasonable Adjustment Solution Ideas
Hidden disability 	Flag on records to alert all staff to needs/adjustments required. Offer/promote Sunflower lanyard to enable visual clue to hidden needs Ensure a Health/Hospital Passport is in place, shared, updated, and followed
Noise/Bright Lighting 	Find/dedicate a quiet waiting area to reduce impact of noise Reduce brightness in dedicated waiting area to reduce sensory stimuli
Anxiety/Anger/Procedure planning 	Offer visits to see and understand the appointment area, meet the staff, carer support and social stories Easy Read information, preparation visits, capacity assessment, advocacy support and continuity of staff
Promoting Understanding 	Double appointment times to ensure time to explain and gain understanding. Provide a simple written/printed summary of advice and actions to follow. Easy Read materials to support information sharing and understanding Ensure carer/support person attends too
Non-attendance 	Carer/family support for appointments Text reminders Non-responders follow up process
Medication/health compliance concerns 	Annual Health checks with a health action plan Medication reviews Carer/family support during appointments Consider specialist referrals for support i.e., Community LD team

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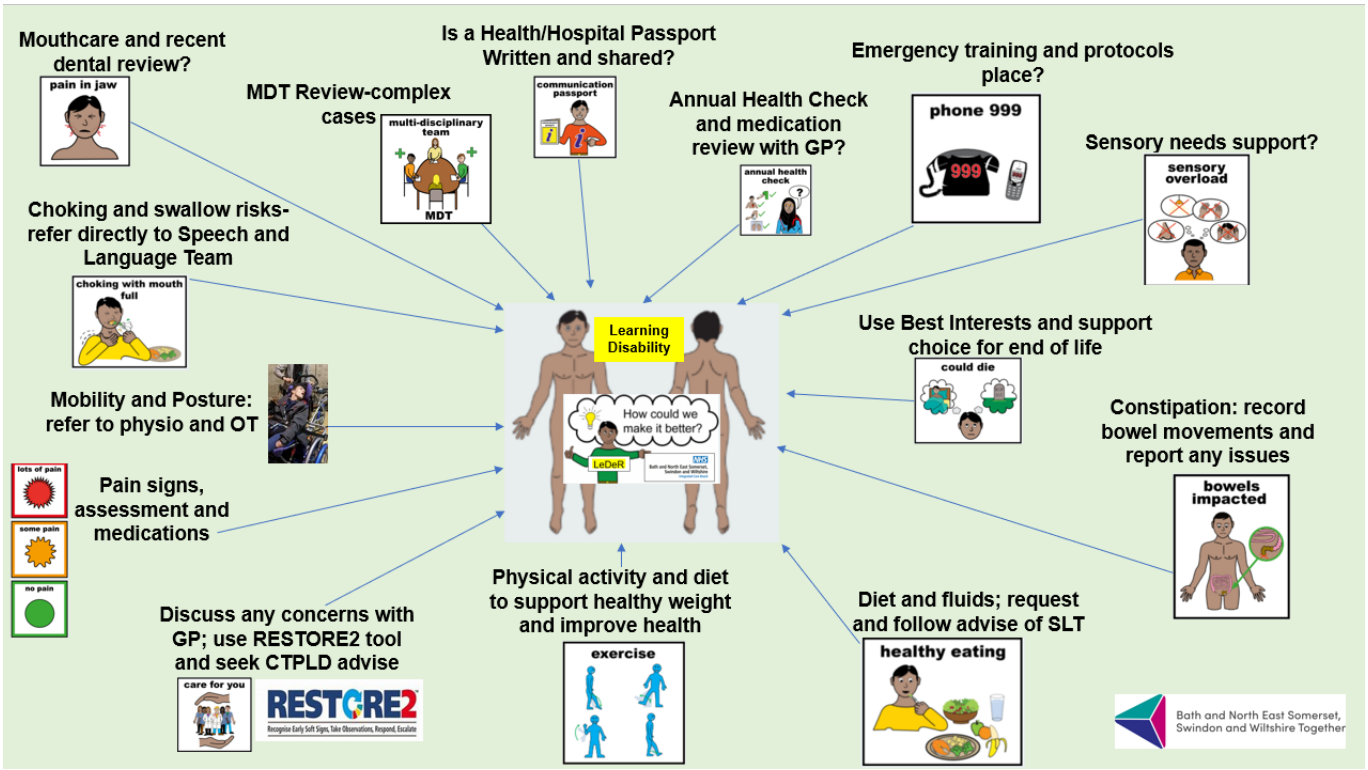
Appendix C: BSW 2022-23 LeDeR Learning Reference Poster



Appendix D

BSW LeDeR Governance Group Members Feedback:

BSW Clinical Lead for Learning Disability and Autism	*'As a GP, I found reading the LeDeR reports extremely hard hitting. The statistics show the significant health inequality people with a learning disability and autistic people experience. The avoidable deaths detailed by LeDeR are indisputable. They are the key reason I am so passionate about improving the care we deliver to people with a learning disability and autistic people. As clinical lead for the ICB, I have tried to consider ways we can take the learning from LeDeR into primary care and to help prevent further avoidable deaths. This has been a big part of my work surrounding improving the uptake of the annual health check for people with a learning disability and autistic people. I have used the learning from LeDeR to focus clinician's attentions on the importance of carrying out the annual health check, carrying out reasonable adjustments, supporting the vaccination uptake and understanding the harms of diagnostic overshadowing'.*
Associate Director, The Great Western Hospital, Swindon.	*'**Quality Improvements (LeDeR learning)*** *The LeDeR mortality programme has been running at the Trust since 2016 as an adjunct to the Trust Structured Judgement Review process (SJR's). The Trust LeDeR reviewer is alerted to the deaths via a monthly report. All learning disability (LD) and autistic person mortality cases are reviewed using LeDeR methodology and are discussed and reported through the Trust Mortality Group and through various internal governance forums and committees at the Trust including the LD Forum.* *Local learning and learning from National audit reports is used to direct the content of internal quality and safety delivery work plans.* ***Project highlights for 2022 – 2023 include*** *1. Development of a diagnostics (radiology) pathway for people with LD* *2. Introduction of 'Changing Places' bathrooms in the main hospital and in the paediatric unit* *3. Delivery of education to front door teams on the application of the Mental Capacity Act for young people with LD*

	4. *Focussed education month within the Emergency Department and the introduction of 'calm' packs* 5. *Learning Disability education at induction and as part of the care certification curriculum for Trust Health Care Assistants* 6. *'Easy read' software option for base wards is being piloted in the Trust* ***Learning for the Trust 2022 – 2023 has prompted the following priority plans for 2023 - 2024*** 1. *Increasing the numbers of 'reasonable adjustment' flags on the Trust electronic patient system that better reflects activity at the Trust* 2. *Focus on patient positioning to optimise respiratory health* 3. *Deliver Year 1 of the Oliver McGowan Training programme* 4. *Introduce 'signalong' sign language into the Trust alongside complimentary communication boards for clinical areas* 5. *Robust MCA practice in relation to the completion of 'ReSPECT' (Decision not to resuscitate) form* 6. *Promotion of the use of the hospital passport* *For all organisations in the ICS there is a strong emphasis on the delivery of the actions coming out of the reviews and holding ourselves to account for delivery, to ensure that there is evidence of service improvement locally. If we get it right there will be fewer preventable deaths because persons who are autistic or have LD will be getting access to timely, advocated, high quality, reasonably adjusted care. The Trust is committed to working to achieve this aim'.*
Salisbury Foundation Trust LD Liaison Nurse	*'I joined in November and that completes a full set of acute liaison nurses in BSW area. We meet on a quarterly basis with Community Learning Disability Teams in Wiltshire* • *Working with South Wiltshire Mencap "Treat Me Well" group to develop workplan that is focussed on -* ○ *Enhancing patient and carer engagement in the Trust.* ○ *Embedding the way, we make reasonable adjustments in our*

	admission and elective planning processes ○ *Review of colorectal screening pathway taking an action learning and co-production approach.* ○ *Supporting multi agency approach to improving outcomes in transition from children's to adult services* • *Facilitated a successful learning day in June that highlighted learning from LeDeR reviews'.*
Learning Disability and Autism Lead, Royal United Hospitals, Bath.	*'The RUH have been delighted to support the LeDeR agenda in recent years, and are committed to improving the lives, and deaths, for our patients with learning disabilities. We have developed some exciting projects over the last year with the aim of reducing health inequalities for people with Learning Disabilities and Autism and improving access to the acute hospital.* *Within A&E, with the support of [a] consultant we have developed 1 page profiles to capture key medical information to guide emergency care and treatment at the front door of the hospital. This has had positive impact in delivering timely treatment, particularly for patients with Addisons Disease and Epilepsy needing specific management plans, for example. We are also piloting an Autism Identification project in ED, and across the hospital where patients can choose to take a card at booking in/reception desks, identifying themselves as autistic to prompt staff to make reasonable adjustments, such as finding a quieter waiting place, or giving more time in consultations.* *Learning from LeDeR reviews has also highlighted a thematic issue of delayed and missed diagnoses for patients with learning disabilities and autism. In response to this, Dr [P] consultant anaesthetist has taken on a lead role to facilitate a pathway offering sedation and GA to achieve diagnostics, scans, and other investigations for patients who wouldn't be able to tolerate such investigations whilst awake.* *Although in its early stages, we have trialled this pathway with patients and are seeking to finalise this soon.*

	Looking ahead, over the next year we are working on developing a reporting pathway with the trust mortality leads, including the trust medical director and lead for claims and inquests, to bring a standardised learning from deaths of patients with Learning Disabilities to the wider staff body. Another key priority for the year, as highlighted in LeDeR reviews is the introduction of a trust STOMP pledge, and conversations with [the] Associate Director for Vulnerable People are already happening to plan this'.
AWP Learning Disability Consultant Nurse	*AWP are committed to supporting LeDeR improvements within AWP and in a system wide approach. We have worked positively on many improvements in the last year and made improvements in general across the last few years. AWP being a part of the LeDeR Governance meetings and the support this group can give is supportive in improving the lives and health care for people with a Learning Disability and/or Autism.* *AWP positive practice includes:* *On-going improvements of hospital passport work within AWP and improving the skills and knowledge of the workforce and an improvement of the patient experience. This work is on-going moving forwards and a key priority for AWP.* *AWP have reviewed the Physical Health Policy and is inclusive for People with a Learning Disability and/or Autism regarding Physical Health Checks on admission (NHS screening and Vaccinations included), Promotion of Annual Health Checks for those diagnosed with a Learning Disability and Hospital Passports (In-patient and community). There is a strong emphasis on the consideration of reasonable adjustments considerations.* *AWP also continue to review other polices so they have wider focus for people with a Learning Disability and/or Autism and inclusion, including the Diabetes Procedure; Care of the Deteriorating Patient Procedure; Recommended Summary Plan for Emergency Care and Treatment Procedure; Fluids and hydration procedure.*

	AWP Dysphagia Policy includes information on Dysphagia in Learning Disabilities, associated risks and vulnerable groups and there is a designated area on AWP Ourspace that links to further guidance on the Speech and Language Therapy page. *AWP responded positively to a risk alert raised from BSW ICB (not direct learning for AWP – system learning) regarding the Increased need for awareness of Choking difficulties and dysphagia and epilepsy This Learning was shared and communicated Trust wide to share learning and resources/policies to support this area of risk for learning and improved care.* *Epilepsy Procedural guidance and additional documents has been published to work alongside the Physical Health Policy. Inclusive of treating patients with a Learning Disability and considerations needed in addition. Risk assessment of areas of daily living are included such as bathing and showering. An elearning training suite is also available via LEARN to complement this guidance and support staff learning and development.* *AWP Softer Signs Work stream which is led by the Physical Health team regarding the implementation of tools to assist with NEWS2 and supporting the assessment and identification of 'softer signs' of physical health deterioration for patients with additional needs such as Learning Disability, Older adults and communication related difficulties. This means staff are better able to identify people who's physical may be deteriorating and seek the right treatment at the earliest opportunity.* *AWP have a regular audit re: STOMP/STAMP [stopping over medicating people with medicines such as antipsychotics, antidepressants, anxiolytics, hypnotics and mood stabilisers] – and elearning modules added to LEARN platform to support learning for staff'.*
D, BSW LeDeR Reviewer	*'LeDeR is a tool of learning from the lives of others who had learning disabilities so as to*

	improve the services provided for other people with learning difficulties. *Being able to contact other professionals, nursing homes and family members [works well].* *Barriers occur when information promised or requested is not provided.* *[Delays have been] waiting for SJR's, NH reports, contacting relatives'.*
N, BSW LeDeR Reviewer	*'Undertaking the reviews is a privilege to be able to see into someone's life and learning from practice that isn't so good but some amazing practice that shows the love and care some of our patients received.* *The QA process has been positive although it means longer for me to complete the review, but it does give a holistic approach and I think has made the review much more informative to get the sense of the person and their journey.* *There has been delays in receiving the information required for a number of my reviews. [The LAC and Coordinator] are incredibly supportive and helpful and I love working for them'.*
G, BSW LeDeR Reviewer	*'Having the mandatory conversation with the GP has allowed reviews to be completed somewhat quicker, but some cases still require that conversation just to understand the fullness of the episodes of care…The number of cases has been unprecedented…Care home closures and take overs by other providers has had an impact on record retrieval which has slowed the progression of cases being submitted'.*

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Appendix E: BSW LeDeR Academy Paper

BSW LeDeR Learning & Sharing

System Action Required

September 2022

Situation, Background, Assessment, and Recommendations (SBAR)

1.1 Following a series of meetings with the BSW Academy Lead, this paper has been prepared to share the BSW LeDeR learning, and system action now required with the evolving BSW Academy for discussion.

Situation	People with a learning disability (LD) and autism (ASD) often face significant health and care inequalities and die prematurely when compared to the rest of the population. A new Health and Social Care Act 2022 requirement has been introduced which requires all CQC registered providers to ensure that staff have the skills and knowledge to support people with LD and ASD via mandatory training and a full code is awaited. The introduction (by Health Education England) of the national role-based Oliver McGowan LD and ASD training is under development following trials. Capacity will be required to deliver and receive the training under three tiers, and the combination of LD and ASD training has generated some resistance. Initial BSW scoping of the proposal does not provide realistic assurance of delivery in practice or that the training will support BSW specific learning and improve outcomes for people. BSW have completed and collated learning from local LeDeR mortality reviews and learning into action delivery across the integrated care system is required.
Background	LeDeR is a service improvement programme that was introduced due to the premature deaths of people with LD. Reviews are undertaken to identify areas of action improvement to reduce the risk of future premature and avoidable deaths. ASD has also been launched into the LeDeR programme in 2022, so all current learning to date within this report is LD related only. However, it is know that there is a higher risk of suicide for people with ASD so awareness raising is required Autistic people and suicidality (autism.org.uk)
Assessment; Learning	**BSW LeDeR Annual Learning Event** A BSW annual LeDeR Learning event was held and recorded on the 19th of July 2022 which shared the 2021 learning.

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BSW LeDeR Learning: Priority Actions

BSW have held a series of workshops to scope two key thematic areas of BSW LeDeR learning for aspiration pneumonia and Health/Hospital Passports:

1. Aspiration Pneumonia

The 2021 reported top causes of LeDeR LD deaths in BSW was aspiration pneumonia (AP), whilst the national 2021 top cause of death was Covid (noting that some of the deaths may have been attributable to Covid in BSW, but not formally diagnosed and recorded).

AP and Dysphagia Risks

LeDeR workshops have identified that dysphagia training is not mandated for all health and care staff. Assumptions were confirmed that staff do not always know how to identify, manage risks and report swallowing issues requiring urgent assessment. This requires consideration and system review for all services.

2. Hospital/Health Passports; Meeting Needs

LD Hospital/Health passports are not always in place, shared or read. These passports help mainstream and specialist services to understand the unique needs and risks for people and how to make reasonable adjustments for them, to meet their needs, likes and dislikes.

BSW will present the findings and proposed recommendations to the BSW ICB LDA Board.

3. BSW Training

BSW LeDeR reviews have identified gaps in training
and awareness of how to support people with LD and ASD. The awaited Oliver McGowan training is hoped to address thus.

	4. Further BSW Thematic Learning from deaths: • Individual risk factors identification and management i.e., recurrent chest infections • Care coordination and handover gaps; Hospital/Health passports are not used or shared which support this • Choice/MCA application/personalised care assurance is missing from reviews i.e., consent and Best Interests • Lifestyle: opportunities to improve daily living and choices, meaningful happy lives and health and wellbeing. • Obesity is an ongoing risk factor noted in BSW. • Annual Health Check/Vaccination/Health Action Plan/Cancer screening; Prevention management; BSW workstreams continues • Low minority ethnic LeDeR notifications; opportunities to increase uptake of vaccinations and other health prevention and promotion initiatives • Nationally constipation has also been an issue.
Recommendations	Discussion required to propose the next steps for: 1. System scoping and mapping of training needs analysis, including gaps across the system 2. Commissioning and piloting the inclusion of LeDeR learning within the new mandatory LD and ASD awareness training 3. Further test and develop the BSW LeDeR Champion pilot role in health and social care; to provide oversight and an action plan to improve knowledge to meet people's needs

National Policy Link:

NHS England » Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021

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