NHS
Bristol, North Somerset
and South Gloucestershire
Integrated Care Board

LeDeR – learning from lives and deaths

Lesley Le-Pine
Associate LD Projects

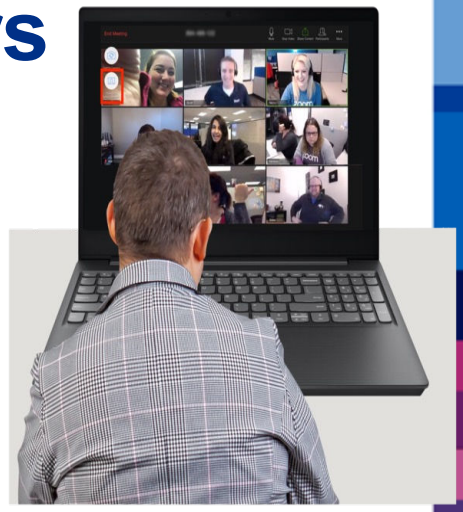
Learning into action

- 62 deaths reviewed last year
- Every one goes to a Quality Case Review Panel
- From this we identify themes to work on
- Everyone project theme this year has been co-produced with people with learning disabilities or autistic people.

Annual Health Checks

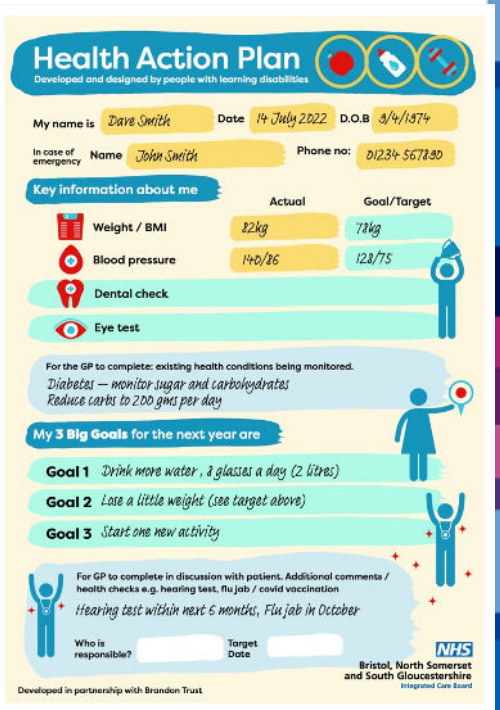
- Average completion of annual health checks in 2021 was 70%
- Target Exceeded - 82% by 31st March
- 98% have Health Action Plans (last year 53%)
- Highest achievement in Southwest region possibly nationally
- Our GP's and practices are amazing!

Working on AHC with service users



- Asked Healthwatch to find out people's experience of health checks
- Held Zoom sessions with small groups
- 'Get Ready' checklist developed for Annual Health Checks
- GP feedback was this saved time and focussed discussions
- paid learning disabled people to work with a designer to develop Easy design HAP which self populates from EMIS
- We commissioned learning disabled actors to make a video to send to patients

https://www.youtube.com/watch?v=dGITBtSSEGo



Tackling Obesity - ‘Healthy Me’ cookery school

- 33 reviews had obesity as a factor
- empower people to understand their body
- people learn to cook & make good food choices
- set up cookery school with Square Food Foundation
- 12 week course for people with LD supported by carers
- before and after food diaries
- learn to cook together - sociable fun sessions
- trying new things to eat
- Certificate at end of course

SQUARE
FOOD FOUNDATION

Outcomes from our healthy eating

- Reducing risk factors of dying
- Planning meals & food shopping with residents
- Changed everyone's eating habits
- Pooing every day! Reduced anxiety from constipation
- All participants now cooked meals at home
- 'Come dine with me' – social activities
- New physical activities – gardening, allotment, fresh herb gardens
- Ann ate only ready meals for 10 years – now cooks fresh every day
- Everyone lost weight over 12 weeks
- 3rd course started in April.

Project outline

Autism Independence

- Explored specific access challenges faced by communities from Somalia, Asia, Poland etc
- Funded by BNSSG
- Gather lived experiences of having a learning disabled person in the family trying to access health services
- Understand the experiences of people moving from child to adult services
- Worked with 42 families

Findings

Autism Independence

- Impact of learning disability/autism on every day life
- Unmet needs, multi dimensional support
- Racial stereotypes influencing decisions
- Lack of cultural intelligence in services
- Lack of engagement from men
- Political context

I was tired due to Ramadan fasting but my parenting skills were questioned. I was treated like I had no clue. No of my queries & worries were addressed by the GP practice

I expect a phone call every day from school, police – anyone. It impacts on my work & my mental health

Racial stereotypes were applied that decided behavioral challenges were rooted in issues at home. No-one visited our home & my son was referred to social services. No-one recognized his autism because our skin is black. I was labelled as a 'trouble' parent.

Addressing health inequalities in minority communities

- Report found Muslim men often disengage from family. All management of health needs falls to the woman & can often lead to a breakdown of the family

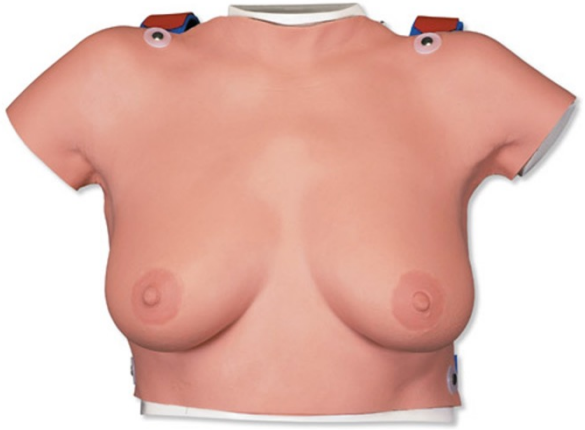
We have funded Autism Independence to develop training for fathers with local Imams & community leaders to address this

- We have funded Care Navigator roles to work with families where first language is not English, directly supporting & signposting people with learning disabilities/autism to access health services. Care Navigators will be recruited from minority ethnic communities.

Poo Matters

- 39 reviews had constipation as a factor
- BNSSG funded pilot and roll out
- worked in partnership with North Somerset People First
- People embarrassed to talk about poo
- Language & shared understanding
- Started Zoom cooking with group during Covid
- People tried recipes - Rated easy or hard to make taste – good or bad
- Reduced anxiety and distress from constipation
- Pooing every day!
- LD nurse conference 400 delegates

Cancer screening



- In top 4 causes of death – often undiagnosed
- Late stage cancers many untreatable
- People with LD not getting equal access to chemotherapy or radiotherapy
- Secured funding for a permanent screening practitioner solely for people with learning disabilities

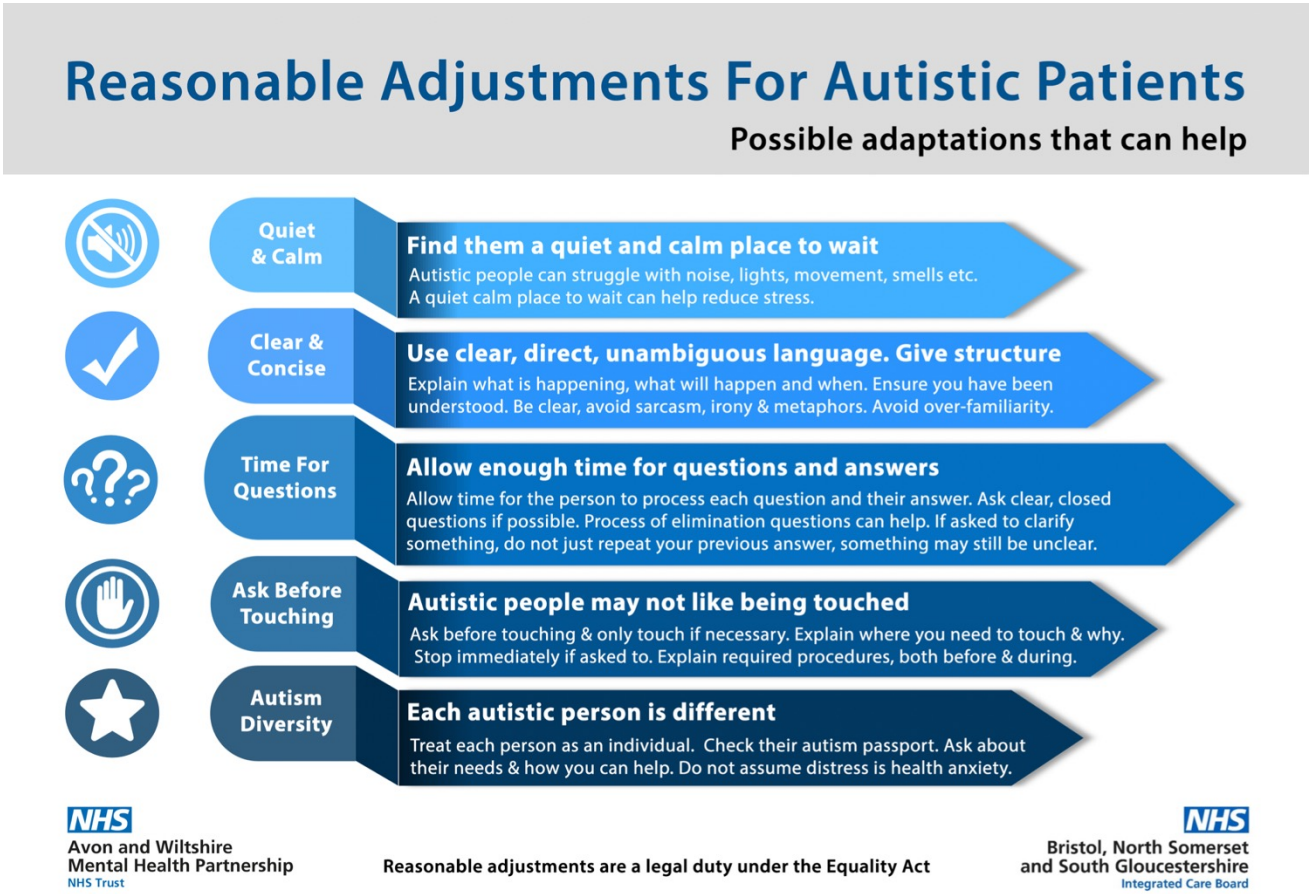
- Teaching self examination to people & carers
- Build self examination into regular routines
- Raise importance of screening with people with learning disabilities and support staff
- Lots of Easy-read information available for screening and cancer
- Great video for breast screening – ‘Do the test’ https://youtu.be/aziJMYMui3s

Autism audit of Emergency Depts

- Developed environment audit tool looking a sensory triggers
- Supported autistic people to audit all four hospital ED's
- Interviewed key staff including handover to psych teams
- Individual reports and recommendations made to each hospital site
- Shortlisted for the national Patient Engagement Awards
- BNSSG funded 25k to purchase reasonable adjustment resources to be made available in all four hospitals

Reasonable adjustments for autistic people

- Guidance developed by autistic people for Emergency Dept staff
- Co-produced training for ED – four sessions at am handover time



Supporting voices of people with learning disabilities

Funded People First across BNSSG with 16 new groups;

- Speaking Up Together groups
- Friendship Cafes
- Green Walking
- Women's wellness
- Men's wellbeing
- Youth voices

Dysphagia project

Swallowing awareness

15% of people with learning disabilities have Dysphagia

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Common signs of dysphagia;

01 choking or gagging on food

02 Coughing, during or after eating or drinking

03 Excess saliva, dribbling & spitting out food

04 Going red in the face or watery eyes when eating or drinking

05 Gurgly wet sounding voice after meals

Choking due to dysphagia or aspiration pneumonia is one of the top 4 causes of death for people with learning disabilities

If you are worried about someone you support, contact a Speech & Language Therapist in the CLDT. Or contact the persons GP

Actions that help

01 Good eating position – sit up straight with feet on floor

02 Keep an upright position 30 mins after eating

03 Plenty of water and sips during meal

04 Eat slowly with small bites. Don't put too much in mouth

05 Supervised meal and avoid talking while eating.

Bristol, North Somerset and South Gloucestershire Integrated Care Board

BNSSG ICB Board Meeting

Date: Thursday 6th July 2023
Time: 12:15
Location: Virtual meeting, to be held via MS Teams

Agenda Number:	6.3.1	
Title:	**Learning Disability Mortality Review (LeDeR) Annual Report 2022 - 2023**	
Confidential Papers	Commercially Sensitive	No
	Legally Sensitive	No
	Contains Patient Identifiable data	No
	Financially Sensitive	No
	Time Sensitive – not for public release at this time	No
	Other (Please state)	Not applicable

Key Points for Discussion:

This is the fourth annual report on the deaths of people with learning disabilities who lived in the Bristol, North Somerset and South Gloucestershire area. The purpose of the report is to share our findings from LeDeR reviews and to report on the programme of work resulting from LeDeR 'Learning into Action' over the last year.

Since the programme began in 2017 there have been 325 deaths reported to the BNSSG LeDeR platform covering the period July 2017 to end of March 2023. There were 62 new cases reported during 2022-2023.

From the completed reviews, 24% of deaths were related to pneumonia as the primary cause, The next most frequently reported cause of death was cancer (16%), sepsis (16%), and multiple organ failure (6%), as the next most commonly occurring cause of death. 3 deaths were due to Covid compared to 7 last year.

Completed reviews and Key Performance Indicators	2018	2019	Jan-20 to Mar-21*	Apr - 21 to Mar - 22	Apr - 22 to Mar - 23
Number of Notifications	42	66	84*	63	62
Number of Closed Completed Cases	4	47	100*	56	65
Allocation of reviewers within 3 months of notification	19%	26%	52.4%	70%	68%

Completion of reviews within 6 months of notification	2.4%	7%	19.9%	35%	31%
QA check of reviews by LAC within 2 weeks of completion.	21.4%	86.4%	100%	100%	100%

**This was a 15 month period due to NHSE changes from calendar year to financial year and included a backlog of cases from the previous year*

The majority of our reviewers were volunteers who undertook reviews in addition to their day job, the majority were nurses, allied health professionals or social workers from Community Learning Disability Teams (CLDT). We have the largest number of active trained reviewers in the South West Region. In order to maintain capacity and consistency in October 2022 we commissioned Sirona Care and Health to provide reviewers from those teams

All of the reviews include a pen portrait of the person who died. For every case we quality check at Quality Assurance Review Panel we always start with reading aloud the pen portrait. This gives us a real sense of the person; their likes and dislikes, their favourite things, what they liked to do, their friends and family, what kind of character and personality they had.

The majority of learning disability deaths (35%) were in the over 75 age group, an increase in age of death from last year showing many people with learning disabilities in BNSSG are living longer However the spread of deaths throughout all age groups for people with learning disabilities is much higher than the general population. We have seen more people living into their 80's and 90's this year but these have been those with fewer co-morbidities and leading fit and active lifestyles.

Ethnicity - We wanted to find out what the barriers are for individuals and families to access health services for adults with learning disabilities and autism. To address this we funded research work with Autism Independence, who undertook a project to reach out to families from Black, Asian and other ethnic communities who have an adult with learning disabilities and/or autism. The purpose was to find out people's stories and experiences of services supporting a person with learning disabilities in the family.

The project report published in January 2023 identified issues and made recommendations to support the Healthier Together vision for people with learning disabilities and autism from all communities to access high quality, fully integrated care that meets their expectations of services.

Every health improvement project we have developed this year has been co-produced with people who have learning disabilities or autistic people.

- Actors with learning disabilities making Annual Health Check videos
- Developing easy read Health Action Plans
- Autism access audit of ED departments
- Co-produced training for ED staff
- Reasonable adjustments resources
- 'Healthy Me' cookery school – tackling obesity and diet
- Poo matters training for carers
- Rebuilding self-advocacy across BNSSG
- Autism Question Time events across BNSSG

Learning themes and actions will be addressed through the Learning Disability and Autism Health Providers Network and reported to the LeDeR Steering Group and the Learning Disability & Autism Programme Board.

We are committed to listening and learning from these reviews, from people with learning disabilities/their families and making real changes across the health care system. We will challenge health inequality and improve health outcomes for people with learning disabilities and aim to prevent people from dying prematurely.

Recommendations:	The BNSSG ICB Board is asked to note the content of the report and recommend it for publication
Previously Considered By:	First draft reviewed by Chief Nursing Officer with amendments for clarity. Subsequently presented and approved by the LeDeR Governance Group and BNSSG ICB Outcome, Quality and Performance Committee with positive feedback about the significant co-produced improvement activity.
Risk and Assurance:	Sustained organisational and system engagement along with funding of co-produce improvement activity is needed to ensure continued activity to reduce health inequalities for this highly vulnerable population.
Financial / Resource Implications:	There is an ongoing cost for paid reviewers and this is addressed through a contract variation with Sirona Care and Health. Ongoing funding will be required for improvement activity associated with learning from LeDeR
Legal and Regulatory:	No legal implications associated with this paper
Equality & Diversity Impact – reducing health inequalities.	Learning themes, recommendations/ actions to reduce health inequalities for people with learning disability are implemented across BNSSG. LeDeR programme focus is on improving equality and diversity outcomes for people with learning disabilities and autism
Patient and Public Involvement:	Involvement of people who have a learning disability in key projects is essential to support learning. All health improvement projects are co-produced.
Communications and Engagement:	There may be some media interest in the annual report. Any requests and responses to media enquiries will be managed and co-ordinated by ICB communications team.
Author(s):	Lesley Le-Pine – LeDeR Programme /Associate Learning Disability Projects
Sponsoring Director:	Rosi Shepherd – Chief Nursing Officer

Bristol, North Somerset and South Gloucestershire
Integrated Care Board

Learning Disabilities Mortality Review (LeDeR) Annual Report

1st April 2022 to 31st March 2023

Learning from deaths of people with a learning disability

CONTENTS

Executive Foreword

The LeDeR Programme (Learning from Deaths Review of people with a learning disability) is led by NHS England and follows on from the work undertaken by the University of Bristol Confidential Enquiry into the premature deaths of people with Learning Disability (CIPOLD) 2013. The findings of that report demonstrated that on average someone with a learning disability lives 20 years less than the general population. However people with learning disabilities in the Bristol, North Somerset and South Gloucestershire (BNSSG) population live 8 years longer than the learning disability national average, however we still have more to do to narrow that gap.

This is the fourth annual report on the deaths of people with learning disabilities who lived in the BNSSG area. The purpose of the report is to share our findings from LeDeR reviews, to report on the identified learning and the action we are taking to improve practice and address health inequalities for people with learning disabilities.

Through the BNSSG LeDeR Governance Group, we have been proud to host vibrant meetings where people with lived experience and system partners have fully engaged with the topics and themes discussed identified in our LeDeR reviews. Everyone has been passionately committed to listening and learning and making real changes across the health and social care system. We continue to challenge health inequality and strive to improve health outcomes for people with learning disabilities with the aim of preventing people from dying prematurely and improving quality of life.

We have continued to work with a range of partners to co-produce activities that respond to the learning from reviews and this is set out in sections five and six

We have been especially proud of the work undertaken by our GP and primary care colleagues this year, who have ensured people with learning disabilities have an Annual Health Check. This is key to ensure people's long-term health conditions are well managed and GP's agree health goals with their patients. The majority of our GP's exceeded the target achieving 82% of completed annual health check for the patients with a learning disability on their register. With 98% of those having a Health Action Plan (last year 54%) 22% of practices completed100% of their Annual Health Checks

Our system partners have worked hard to address health inequalities and improve access to healthcare for people with learning disabilities and autistic people. Our goal is to create a strong culture of person-centred care, working alongside people with lived experience, to be vigilant and proactive supporting people to speak up in our communities.

Rosi Shepherd
Chief Nursing Officer

Section 1 – Our structure for LeDeR

Background

The Learning Disabilities Mortality Review Programme (LeDeR) was established in 2016. It is a non-statutory process set up to contribute to improvements in the quality of health and social care for people with learning disabilities in England. All deaths of people with learning disability over the age of 4 years are subject to a Learning Disability Mortality Review.

The main purpose of the LeDeR review is to:

- Identify any potentially avoidable factors that may have contributed to the person's death,
- Identify learning and plans of action that individually or in combination, guide necessary changes in health and social care services in order to reduce premature deaths of people with learning disabilities.

All Clinical Commissioning Groups areas were required to establish a LeDeR Steering Group during 2017/18. The local LeDeR process and governance is a key responsibility for the new Integrated Care Systems(ICS) throughout this year.

Overview of the national LeDeR process

The national LeDeR Programme, run by NHS England introduced a new national policy in April 2021 to build on the programme developed by the University of Bristol. The reviews focus on the individual's last year of life and include a pen portrait describing who the person was, their likes and personality, followed by a review of any medical and social care the person received. Importantly, the review includes making contact with a member of the family or staff carer to ensure any queries or concerns they have are answered in the review and their involvement in writing pen portraits is key. The LeDeR guidance states that these are not investigations, but reviews, with the focus on identifying learning and not apportioning blame.

The reviewer looks to identify best practice by reviewing the person's health and social care records and where identified, areas where improvements could be made. There is either an initial review or a new focussed review - introduced into the process with the new policy. All reviews concerning someone from a black or minority ethnic background automatically becomes a focussed review. In January 2022 NHSE introduced LeDeR reviews for autistic people who do not have a learning disability.

Our Local BNSSG LeDeR structure

LeDeR Governance Group

The Executive Lead responsible for the programme is the ICB Chief Nursing Officer. The LeDeR Governance group has met monthly since February 2019 including throughout the lockdown periods.

Representatives attend the Governance Group from all BNSSG health providers, the three local authorities which provide adult social care, the Care Quality Commission, GPs, local housing providers of services to people with learning disabilities and NHS England regional LeDeR leads.

Our LeDeR Governance Group is chaired by the Chief Nursing Officer as Executive lead of the Governing Body for the Integrated Care Board (ICB). The group takes strategic level oversight of the reviews of deaths of people with learning disabilities and drives transformation to improve care. The role of the LeDeR Steering Group is to:

- Guide the implementation of the programme of local reviews of deaths of people with learning disabilities
- Receive regular updates from the Local Area Contact (LAC) about the local reviews of deaths of people with learning disabilities
- Monitor action plans resulting from local reviews of deaths
- Take appropriate action as a result of information obtained from local reviews of deaths
- To support the identification of and sharing of best practice in the review process
- Provide assurance to the Outcomes Performance and Quality Committee and the ICB Governing Body
- For committee members to provide shared governance for LeDeR and reporting back to their own organisations

Assurance updates are reported to the Outcomes, Performance and Quality Committee and via the group's minutes of meetings and quarterly governance reports. The Outcomes, Performance and Quality Committee provides assurance and detailed update reports on LeDeR to the Governing Body.

To support the LeDeR process within BNSSG we have a LeDeR Framework policy providing clear guidance on the process and governance to support the learning from reviewing these cases. The policy is available on the ICB's website.

Clinical Quality Assurance Review Panel

To strengthen the BNSSG LeDeR quality assurance process, we introduced a local additional stage of a Clinical Quality Assurance Review Panel. It is important to us that we have assurance of the content and the quality of individual reviews. The panel was first established in July 2019 and membership includes the Local Area Contact, Clinical Lead GP for Learning Disabilities, GP Safeguarding Clinical Lead, CCG safeguarding representative, local authority representatives, social workers and the LeDeR administrator.

The panel reviews all completed cases to ensure all questions have been fully answered, with learning and best practice identified, with appropriate recommendations formulated prior to closing the case on the LeDeR platform. The panel also identify themes from each review to guide topics for further action.

The LeDeR Team

The Local Area Contact (LAC) is the manager of the BNSSG LeDeR process ensuring it meets targets and delivers the programme day to day. The LAC oversees the allocation of cases to trained LeDeR reviewers, monitors the progress and completion of reviews and promotes quality assurance in the closure process of each case. The LAC prepares content, agenda and papers for the LeDeR Governance Group, Quality Committee and Governing Body.

A LeDeR administrator supports the LeDeR reviewers with case allocations, tracing records from GP's, providers from both health and social care, following up queries and generally supporting reviewers with each case. The administrator undertakes preparation of papers and minutes for Quality Assurance Review Panel and LeDeR Governance Group.

LeDeR Reviewers

The LeDeR process is supported by a team of trained reviewers from healthcare organisations across BNSSG, from acute hospital Trusts and Community Learning Disability Teams (CLDTs). In the first half of the year the majority of our LeDeR reviewers were volunteers who undertook reviews in addition to their usual role, many of them are clinical professionals working in hospitals or in the community so they sometimes have limited time to dedicate to complete reviews. This year, most have returned to their main clinical role as services returned to face to face work with clients. In October 2022 we commissioned Sirona Care and Health to provide LeDeR reviewers on a paid rather than voluntary basis. We also had two paid independent senior reviewers who were available to undertake more complex reviews and provide support to the other reviewers.

Over the last year we trained a total of 18 reviewers on the new platform, 14 of these reviewers have been active on cases this year. We have two dedicated independent reviewers who are paid for the cases they complete. They have retired from the NHS but have extensive years of experience at a very senior level, both having been former Directors of Nursing.

Buddy Reviewer system for first LeDeR Review

To support reviewers with their first few reviews we set up a 'Buddy System'. Buddies are reviewers with experience of completing several LeDeR reviews and have a wealth of knowledge on the process. The buddies act as a point of contact for advice on where to start, how to approach providers and families and how to ensure their review is of good quality. Buddies provide a safe confidential space to discuss issues and support best practice for new reviewers.

Peer Support Meetings

In addition to the Buddy System, we established Peer Support Meetings to offer additional support to our LeDeR reviewers. Meetings are bi annual and the aim is to support reviewers with their open cases. This is the reviewer's additional opportunity to tell the LAC of any issues or blocks they may be facing and share their experiences and ideas with other local reviewers. These meetings also give the LAC an opportunity to update reviewers on information from the Governance Group, Regional meetings and other LeDeR relevant events. Reviewers are also able to update themselves on any emerging themes or their individual needs, such as training and support.

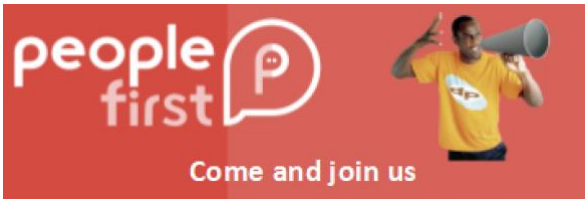
Sirona has taken on the support meetings for their reviewers, through having a safe space to raise any concerns or speaking to other reviewers as to how they might approach a situation.

LeDeR Service User Forum

We established a LeDeR Servicer User Forum in partnership with North Somerset People First, comprising of members with learning disabilities. We were only able to meet twice before lockdown. However we have continued to look for creative ways for service user voices to contribute to the Steering Group; through service user led reports about how they were coping with Covid-19 and any emerging issues, presentations about service user audits and service user projects related to LeDeR themes such as constipation.

In 80 out of 100 LeDeR reviews last year people had constipation. We funded North Somerset People First to co-produce a project and training on constipation.

We have worked closely with People First this year and commissioned them to provide 16 new advocacy, health & wellbeing and friendship groups across BNSSG.



Learning Disability and Autism Health Providers Network

Our local structure across the learning disability and autism is the Health Providers Network. It has representation from all the health providers in secondary, primary and community care who work with adults with learning disabilities and/or autistic people. We wanted to move actions identified from LeDeR from the governance group to provider organisations.

The Learning Disability and Autism Health Providers Network is an action-oriented group, which takes learning from national and local key themes and trends from LeDeR to ensure the associated quality improvement takes place, and that there is consistency in practice and care for patients with learning disabilities, across NHS providers in BNSSG. The networks overall aims are:

- To agree a programme of joint service improvement initiatives as a result of the health themes coming from LeDeR.
- To act on outcomes from local reviews, identify areas of good practice for development work in preventing premature mortality, and areas where improvements in practice could be made and act on those.
- To ensure that the work programme actively captures and shares local and national learning; aligned to Learning from Lives and Deaths initiatives.
- To take the health learning from national and local key themes and trends, and ensure the associated service improvement takes place.
- To develop health innovations and share best practice between providers to ensure continued quality improvement across services.
- To respond to any resulting LeDeR Focussed Review action plans or recommendations developed as a result of the reviews and take appropriate action as a network to address service shortcomings and identify improvement.

The network agreed a three-year work plan to address issues identified in reviews such as;

- Undertake a review to ensure End of Life Pathways are appropriately used and fully involve people with learning disabilities and their families, including the use of accessible information and ReSPECT plans.
- Hospitals should identify people with learning disabilities who have repeat admissions for constipation related issues and flag this to GPs in discharge letters.
- Complete a DNACPR audit to ensure order decisions are appropriately made with assessments for mental capacity and best interests assessments fully completed.
- Reasonable adjustments and risk assessments must be in place for everyone with dysphagia appropriate to their living environment - to ensure they are effectively supervised with drinking and swallowing at mealtimes/snack time to avoid choking
- Respiratory specialists need to be involved in improving access and treatment for people with learning disabilities with respiratory conditions to prevent people from dying prematurely
- Reasonable adjustments to be made for people with learning disabilities and for autistic people for appointments, health tests & investigations in primary and secondary care

Section Two – Programme Performance

Deaths notified to the LeDeR programme

Since the programme began in 2017 there have been 325 deaths reported to the BNSSG LeDeR platform covering the period 1st July 2017 to 31st March 2023.

In June 2021 the LeDeR platform, moved from the University of Bristol to NHS England. With NHSE now managing the LeDeR platform and introducing a new national LeDeR policy there have been a number of changes.

The NHSE operating platform for managing reviews went live in July 2021. Review forms were redesigned with 'Initial' and 'Focussed' reviews which replaced the MAR process. All reviewers had to re-train before they could access the platform and be allocated reviews. There were some teething problems as there are with any software changes but these have largely been resolved through regular dialogue with the regional and national team.

The table below provides a summary of the status of all cases as at 31st March 2023.

Table 1: Summary of deaths notified in 2022/23

Total notifications 1st April 202 to 31st March 2023	62
Total notifications not yet assigned to a reviewer (to March 2023)	5
Total number of reviews currently in progress	19
Completed and closed reviews in 202/23*	65

*includes 3 reviews completed from last year.

NHSE/I key performance indicators for LeDeR activity require reviews to be allocated to a reviewer within 3 months of notification, for reviews to be completed within 6 months of notification and the quality assurance of initial submitted reviews by the LAC within 2 weeks of completion before taking to panel.

Autism only deaths notified

In January 2022 NHSE introduced LeDeR reviews for autistic people who do not have a learning disability. Since January 2022 to 31st March 2023 two 'autism only' deaths were notified to BNSSG. Both were suicides that have been reported and investigated through police investigation, Coroners inquest, Serious Incident Review and Safeguarding investigation as well as LeDeR.

Table 2: Completed reviews and KPI's

Completed reviews and Key Performance Indicators	2018	2019	Jan-20 to Mar-21*	Apr - 21 to Mar - 22	Apr - 22 to Mar - 23
Number of Notifications	42	66	84*	63	62
Number of Closed Completed Cases	4	47	100*	56	65
Allocation of reviewers within 3 months of notification	19%	26%	52.4%	70%	68%
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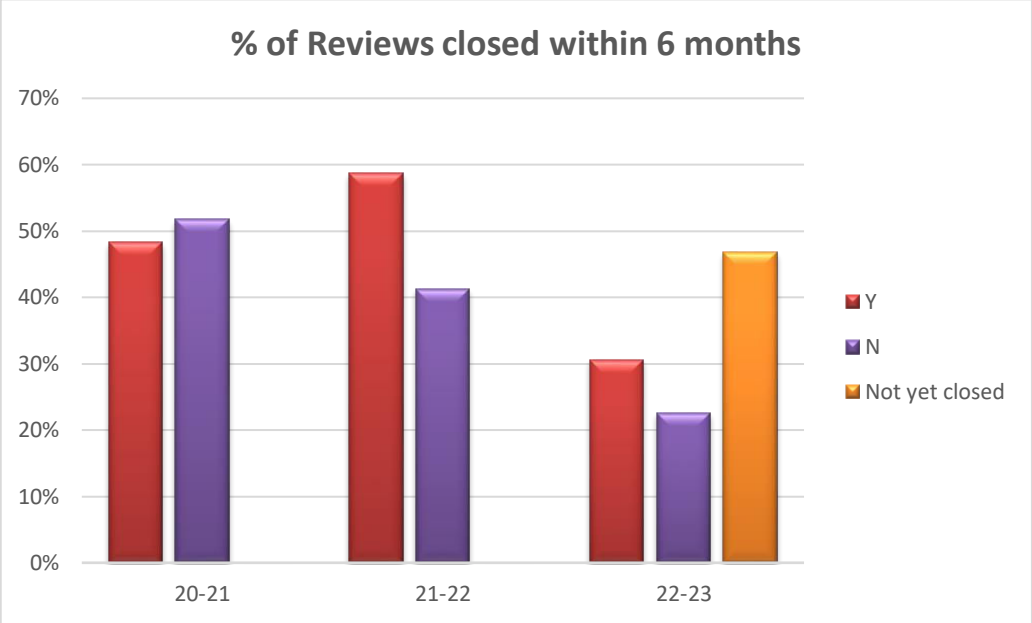
Graph 1:



Actions taken to address Key Performance Indicator's

KPI performance with allocation has had a 2% reduction in allocating cases and a 4% reduction on completion of cases. This is due to the availability of Sirona reviews both to allocate cases and for completion of cases. This is being addressed by Sirona recently establishing dedicated reviewers.

The new initial reviews have shorter forms with lots of tick boxes. We find the new review forms lack depth and we introduced a checklist for our reviewers to ensure key information is included. Working from home during lockdown increased the opportunities for clinical teams to support this work. However as lockdown has ceased, clinical teams have had to prioritise face-to-face work with clients which reduced the capacity of our reviewers.

We have a weekly follow-up with reviewers with a tracker to ask how their cases are progressing, checking if they need any support from us to access notes or querying if there is anything that is delaying them from completing the review.

The Quality Assurance Review Panel met quarterly as cases were not completed during the transition to Sirona reviewers but this was back on track in Quarter 4

LeDeR Reviewers

In the first half of the year the majority of our reviewers were volunteers who undertook reviews in addition to their day job, the majority were nurses, allied health professionals or social workers from Community Learning Disability Teams (CLDT). We have the largest number of active trained reviewers in the South West Region. In order to maintain capacity and consistency in October 2022 we commissioned Sirona Care and Health to provide reviewers from those teams

We are especially proud of, and grateful to, all our reviewers who are dedicated to completing high quality reviews. Not only have they engaged fully with the review process but have personally reflected on the reviews to embrace learning for their own practice.

Summary of best practice examples
• Care home went above and beyond, family very happy with care, she had a very happy life. Love by staff and enjoyed parties and celebrations.
• Although blind, family said their son had excellent supported living – with staff arranging regular massage, outings, church on Sunday, audio books etc
• Excellent co-ordination of care and carers tailoring opportunities such as playing piano and taking him to recitals of classical music
• Advocating on the person's behalf with ambulance staff, insisting person was taken to hospital.
• Many examples of the Learning Disability and Autism Liaison Team making timely assessments and supporting people in hospital which significantly improved their care
• Staff fundraised to buy him a bike so he could visit friends and family independently
• Good support from GP, Care staff went the extra mile to arrange visits to Pakistan despite having profound disabilities and a rare condition
• Effective follow up from GP and primary care team when discharged from hospital
• Lots of examples of collaborative working and involvement of family members
• Everyone had all three doses of Covid vaccination except one individual who chose not to following discussion with his family, none of whom were vaccinated
• 90% of reviews showed that people had their flu vaccine

• Good Best Interests meeting about having a PEG fitted, accessible information provided and person chose not to have a PEG fitted as food was central as he really enjoyed eating and drinking
• GP's regularly visiting Care Homes and building great rapport with residents and staff
• Care homes advocating for individuals not to move when health needs changed so they could stay in their home of 30+ years

Summary of improvement recommendations – individual reviews
• Significant weight loss of 7kg in a short period should be investigated. Regular monitoring or sudden weight loss and taking action when the person has a low BMI
• Poor transition to adult service, no CLDT as an adult, lack of support for carers
• Ensure sepsis guidelines are followed in hospital to identify sepsis in the learning disability population which may be overlooked due to diagnostic overshadowing
• Unknown to local authority, improve communication between agencies - became an illicit drug user. Mum had concerns nobody talked to each other to join up care
• Placement reviews need to take place regularly to ensure people are in an appropriate placement and accommodation that is suited to their needs
• Reasonable adjustment of taking blood from foot rather than arm as recommended by mother as son reacted if he saw the needle
• Checking learning disabled patients for pressure area injuries during prolonged hospital stays
• Training/awareness for residential staff identifying vital signs and when to refer to End of Life and Palliative care services for guidance and advice
• Delays to putting DOLs in place whilst people were in hospital
• Carers assessments to be completed for those living with a family member
• Hospitals to ensure death notifications are sent to GP's

Section 3 - About the people who died

Pen Portraits

All of the reviews include a pen portrait of the person who died. For every case we quality check at Quality Assurance Review Panel we always start with reading aloud the pen portrait. This gives us a real sense of the person; their likes and dislikes, their favourite things, what they liked to do, their friends and family, what kind of character and personality they had.

We have learned of wonderful people; who liked good company, visiting friends and family, those who like a party and entertainment. A great character who was an Elvis impersonator who entertained everyone he lived with and went to lookalike contests. We have heard about the lives of people who were married, some had children. Friendships are especially important in peoples lives.

Everyone loved travel, being by the sea or going abroad. Most people loved food and trying new dishes – fish and chips a firm favourite, a lot of spicey food fans with regular curry nights in the home. Some people were staunch meat and two veg, enojoying the foods they had growing up. Jelly and rice pudding featured large! People were big music fans, enjoyed concerts, theatre and music from Abba, Hank Marvin to classical concerts, people who were the life and soul of the party to people who preferred their own company. Many people enjoyed films and going to the cinema, several Harry Potter fans who had been on the studio tours. Many keen gardeners and people loved having pets, visits to the zoo and farms were especially popular. We learnt about people who liked to look smart, took care of their appearance, loved getting their hair done and painting their nails.

Family was central for many individuals, being supported to keep in contact - with ipads for those who lived abroad, inviting family to tea, new babies, nieces and nephews – important to be supported to be part of family celebrations. All the people were so well loved by family and their carers. Faith and religion was important to many people and the sense of community from regular attendance at church. Maintaining friendships and supporting people to stay in regular contact was also evident, especially when people aged or their mobility changed

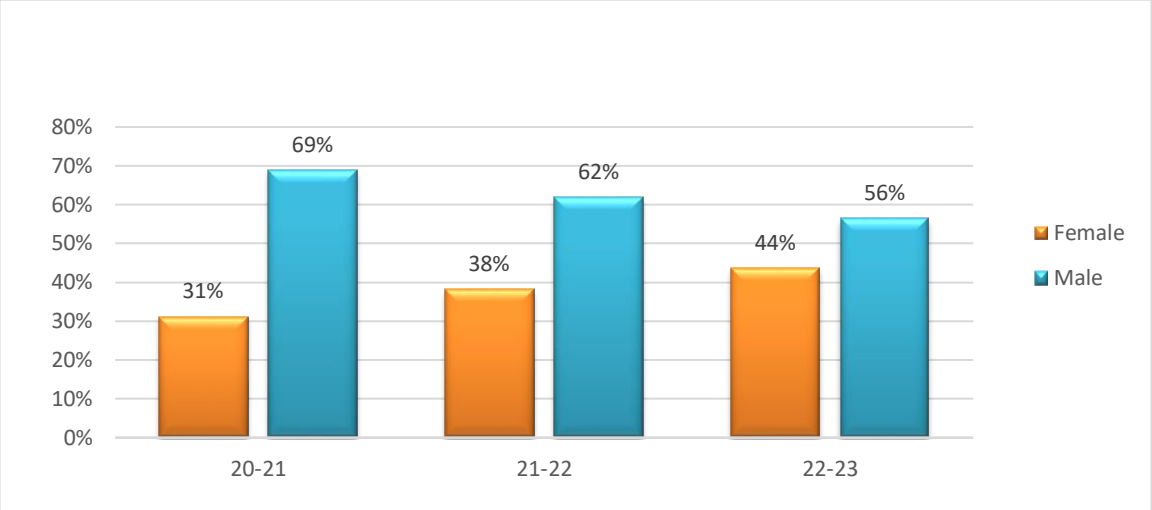
These portraits help us connect to the person and remind us to consider whether the care and treatment they received would have been good enough if it was our relative, our sister, our son, our grandma.

Demographic data

The following graphs provide the demographic information of those that died.
Graph 1 shows the gender of those who died. 56% of deaths reported were male and 44% were female. We do not have comparisons with regional and national data as it is not yet available.

Nationally the population of people with learning disabilities is younger and more dominantly male than the general population so it is important to make allowance for these characteristics in evaluating the number of deaths. There is prevalence for more men to be diagnosed as having a learning disability as many syndromes are XY linked conditions.

Graph 2: Gender of those who died.



Graph 3: Median Age of death

Median Age of Death	BNSSG LeDeR		BNSSG general population	
	Male	Female	Male	Female
April 2022 – Mar 2023	68	59	80	85

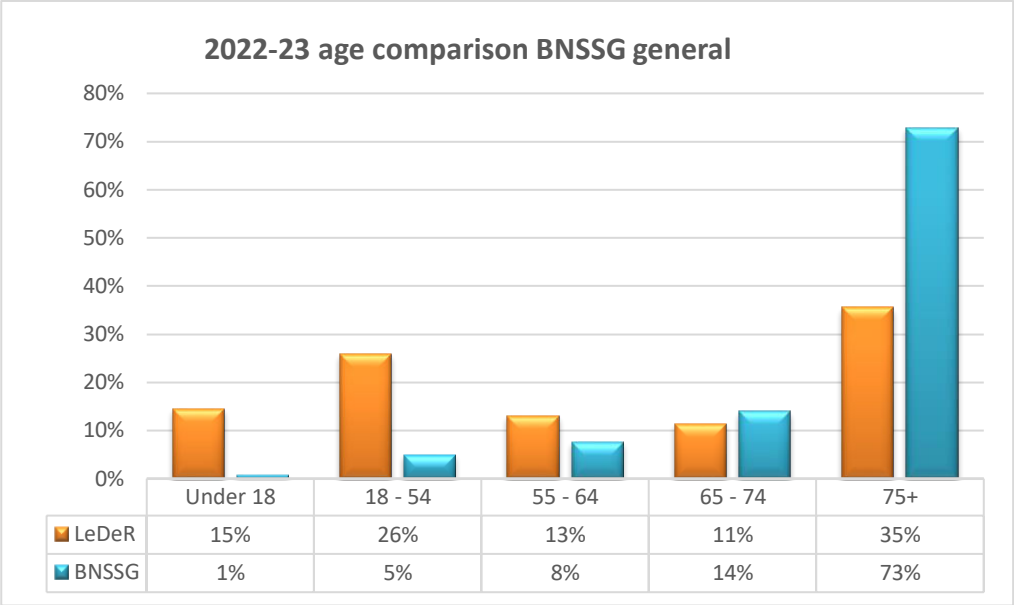
	BNSSG LeDeR		BNSSG LeDeR Overall	South West LeDeR	National LeDeR
	Female	Male			
2022/23	67	71	68	62	62

Reviewing the comparative data men with a learning disability live slightly longer than women with a learning disability but die 12 years younger than the general BNSSG population. However people with learning disabilities in the BNSSG population generally live 6 years longer than the learning disability national average. According to Kings College London the national median age of death has increased in 2021 by 2 years. https://www.kcl.ac.uk/research/leder

The majority of learning disability deaths (35%) were in the over 75 age group, an increase in age of death from last year showing many people with learning disabilities in BNSSG are living longer (Graph 4). However the spread of deaths throughout all age groups for people with learning disabilities is much higher than the general population. We have seen more

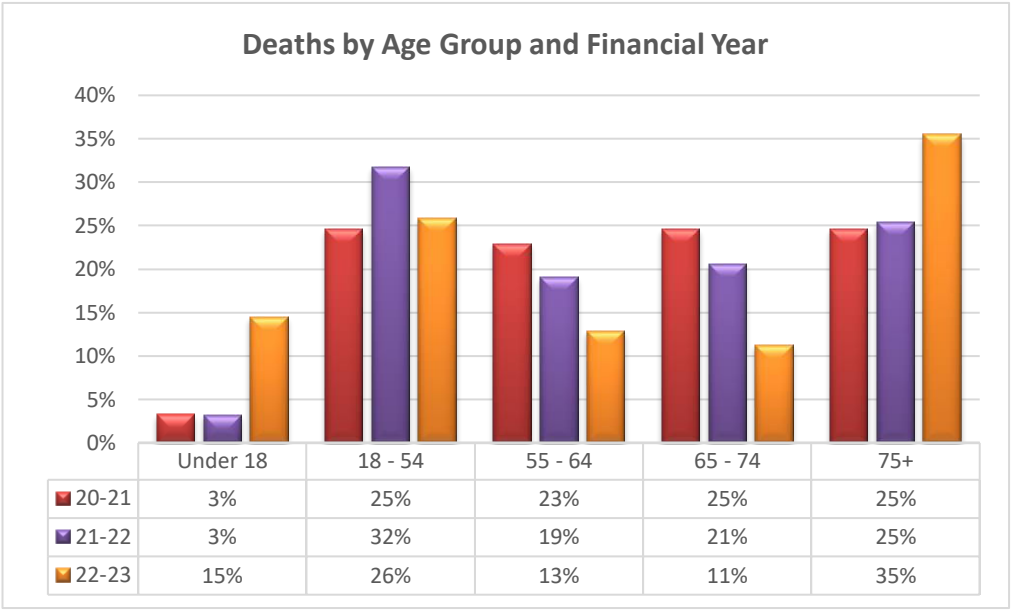
people living into their 80's and 90's this year but these have been people who had fewer co-morbidities and were leading fit and active lifestyles.

Graph 4: Age range of deaths reported compared to general population



	Under 18	18 - 54	55 - 64	65 - 74	75+
LeDeR	15%	26%	13%	11%	35%
BNSSG	1%	5%	8%	14%	73%

Graph 5: LeDeR age range of deaths reported by financial year



	Under 18	18 - 54	55 - 64	65 - 74	75+
20-21	3%	25%	23%	25%	25%
21-22	3%	32%	19%	21%	25%
22-23	15%	26%	13%	11%	35%

Child death data

During 2022/23 there were 8 cases notified to the LeDeR platform, which related to the death of a child with learning disabilities, an increase of 12%. All the children had profound and complex disabilities with multiple co-morbidities. All child deaths are reviewed as part of the statutory Child Death Overview Process (CDOP) and therefore separate LeDeR reviews are not undertaken. The CDOP reviews have a considerable backlog and NHSE has decided to remove CDOP cases from the LeDeR reporting system from 1st July 2023.

Ethnicity

Graphs 6 and 7 below show the ethnicity of deaths reported to the LeDeR platform. Although we have had a few more deaths reported from Black and other minority ethnic communities this year, there continues to be a low number of learning disability deaths reported from these communities. This does not compare with the demographic profile for BNSSG and we believe there may still be under reporting of deaths from these communities.

People with learning disabilities and/or autism experience health inequalities and those in ethnic minority communities are further disadvantaged and under-represented as users of learning disability and autism health services.

We wanted to find out what the barriers are for individuals and families to access health services for adults with learning disabilities and autism. To address this we funded research work with Autism Independence, who undertook a project to reach out to families from Black, Asian and other ethnic communities who have an adult with learning disabilities and/or autism. The purpose was to find out people's stories and experiences of services supporting a person with learning disabilities in the family.

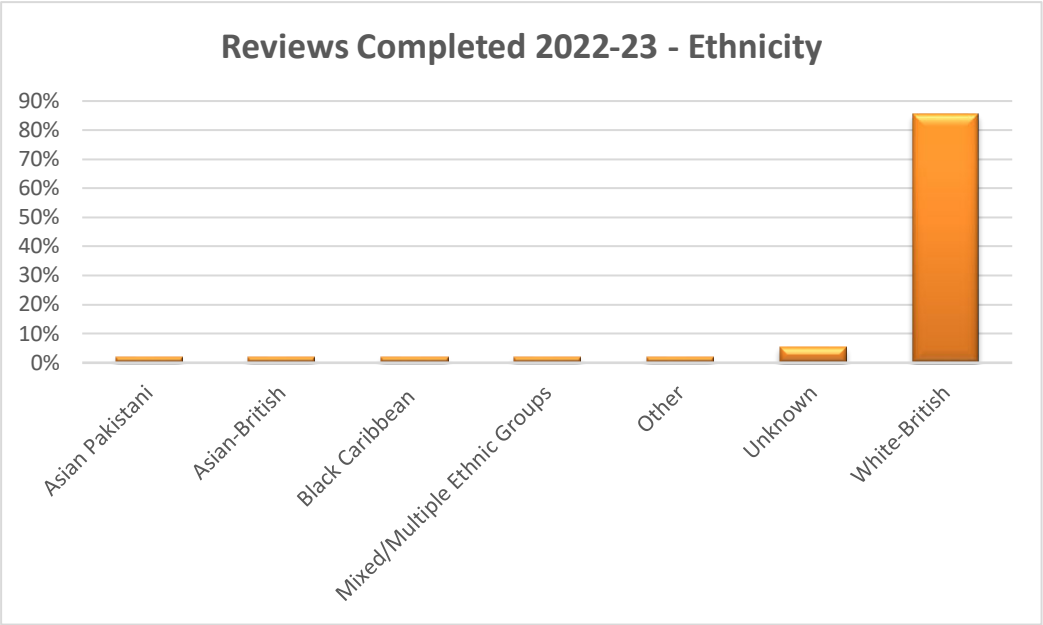
The project report published in January 2023 identified issues and made recommendations to support the Healthier Together vision for people with learning disabilities and autism from all communities to access high quality, fully integrated care that meets their expectations of services. We wanted to hear stories of peoples' past and current experience – listening was the first step. Initially, work has had a BNSSG focus. Project findings and recommendations have been shared with colleagues in the South West Region. There are two projects BNSSG is commissioning to address the recommendations.

- Muslim families are often in the position of having one or more profoundly learning disabled/autistic child in the family. The report identified that Muslim men often disengage from family. All the management of health needs falls to the woman and can often lead to a breakdown of the family and relationship. BNSSG is funding training and workshops for fathers with local Imams and community leaders to address this

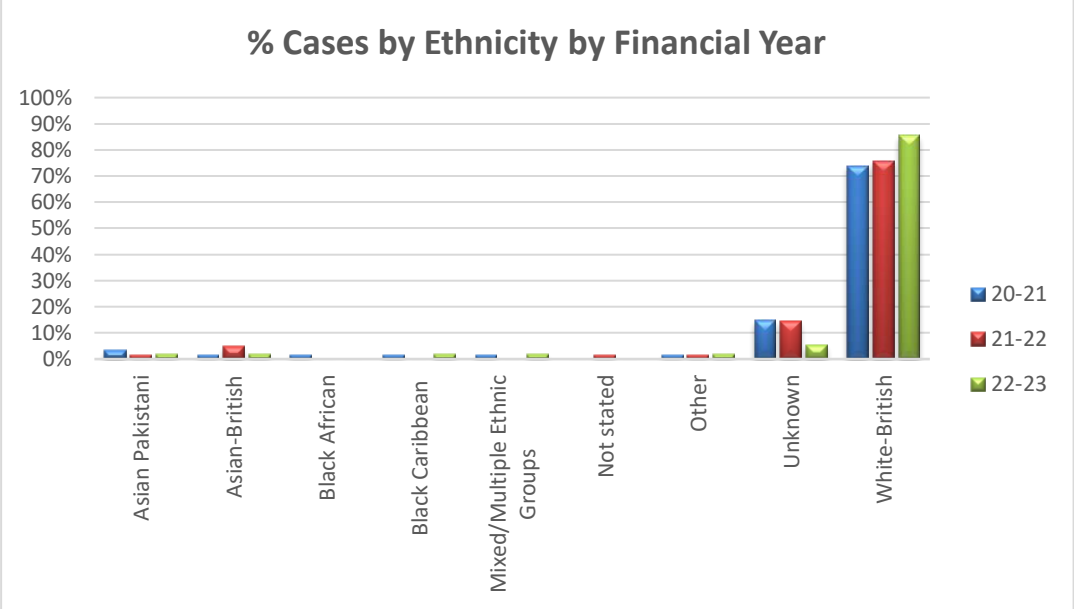
- There was poor health engagement with AHC, screening programmes, health appointments etc. BNSSG will commission Care Navigator roles to work with families where first language is not English, directly supporting, and signposting parents/young people with learning disabilities/autism from ethnic communities in accessing health services. Care Navigators will be recruited from minority ethnic communities.

L-R Nura Aabe, Founder Autism Independence, Rosi Shepherd CNO, Aga Kowalska - Autism Independence, Shane Devlin, CEO BNSSG

Graph 6 – Number of completed cases by ethnicity



Graph 7 – Completed cases by ethnicity – year comparison



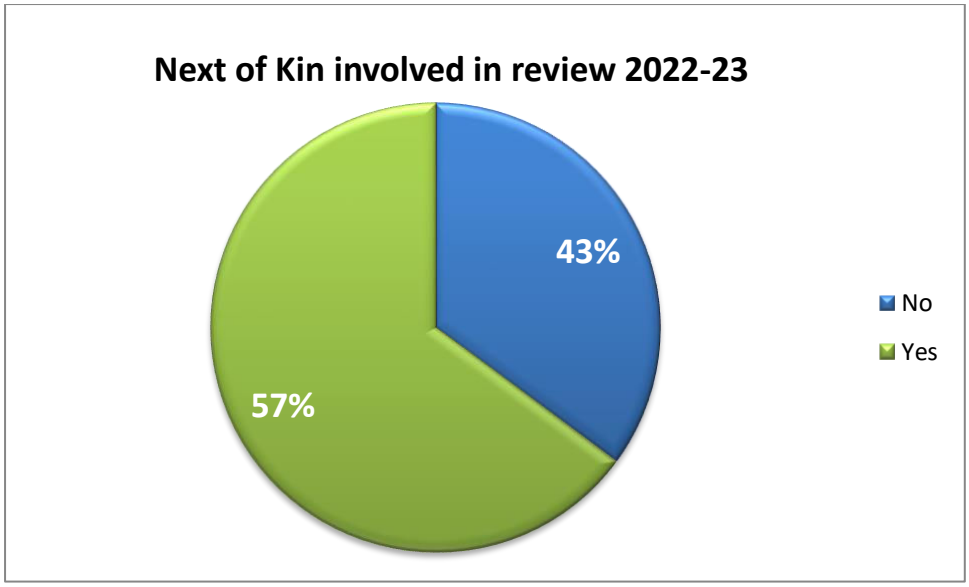
	20-21	21-22	22-23
Asian Pakistani	2	1	1
Asian-British	1	3	1
Black African	1		
Black Caribbean	1		1
Mixed/Multiple Ethnic Groups	1		1
Not stated		1	
Other	1	1	1
Unknown	9	9	3
White-British	45	47	47

Involving next of kin in reviews

We have collected data again this year on whether next of kin were involved in the review process. 57% of reviews included next of kin. Sometimes parents but more usually due to people's age, a brother, sister, niece or nephew. Where people have previously lived in long stay hospitals family connections were often lost. Care providers have made special efforts over the years to re-connect people to family sometimes successfully, sometimes not.

We have also found in reviews where there was no next of kin, that care staff who knew the person really well was involved in the review. Some care staff have known their residents for twenty, thirty years or more and have very close relationships.

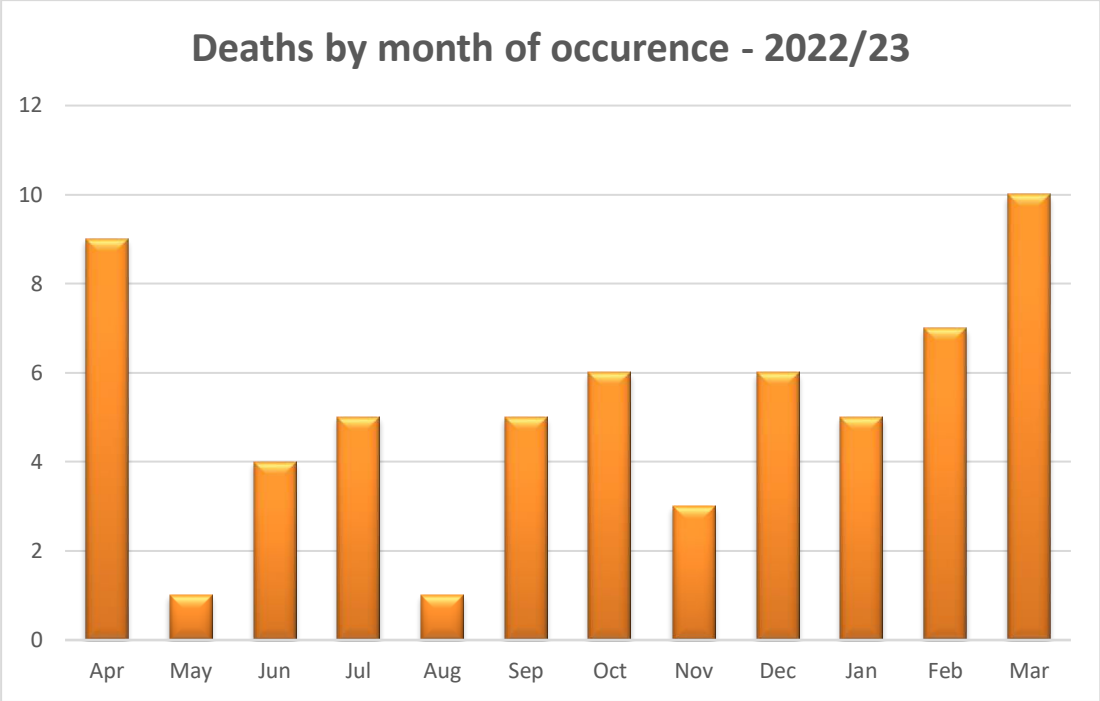
Graph chart 8



Section 4 – Cause of death

Highest month with 13 deaths was in March 2023, similar to last year. Deaths were mostly attributable to pneumonia's. There were three Covid-19 deaths this year a reduction from seven deaths last year.

Graph 9: Month of death

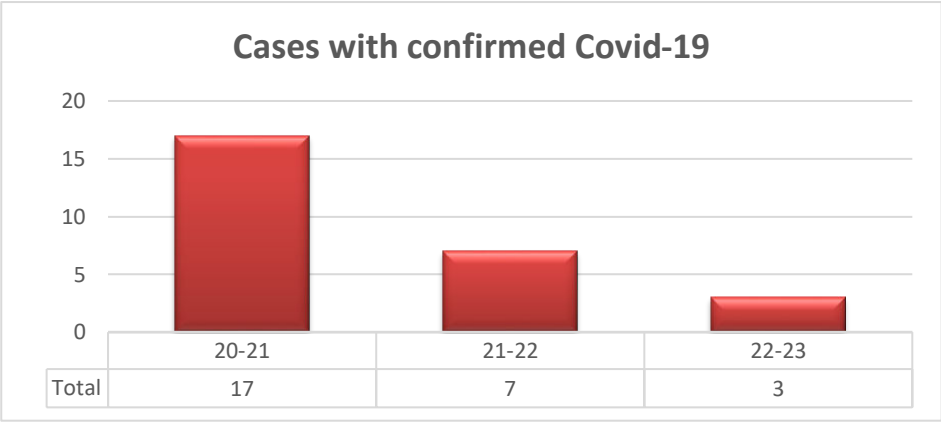


Cause of death

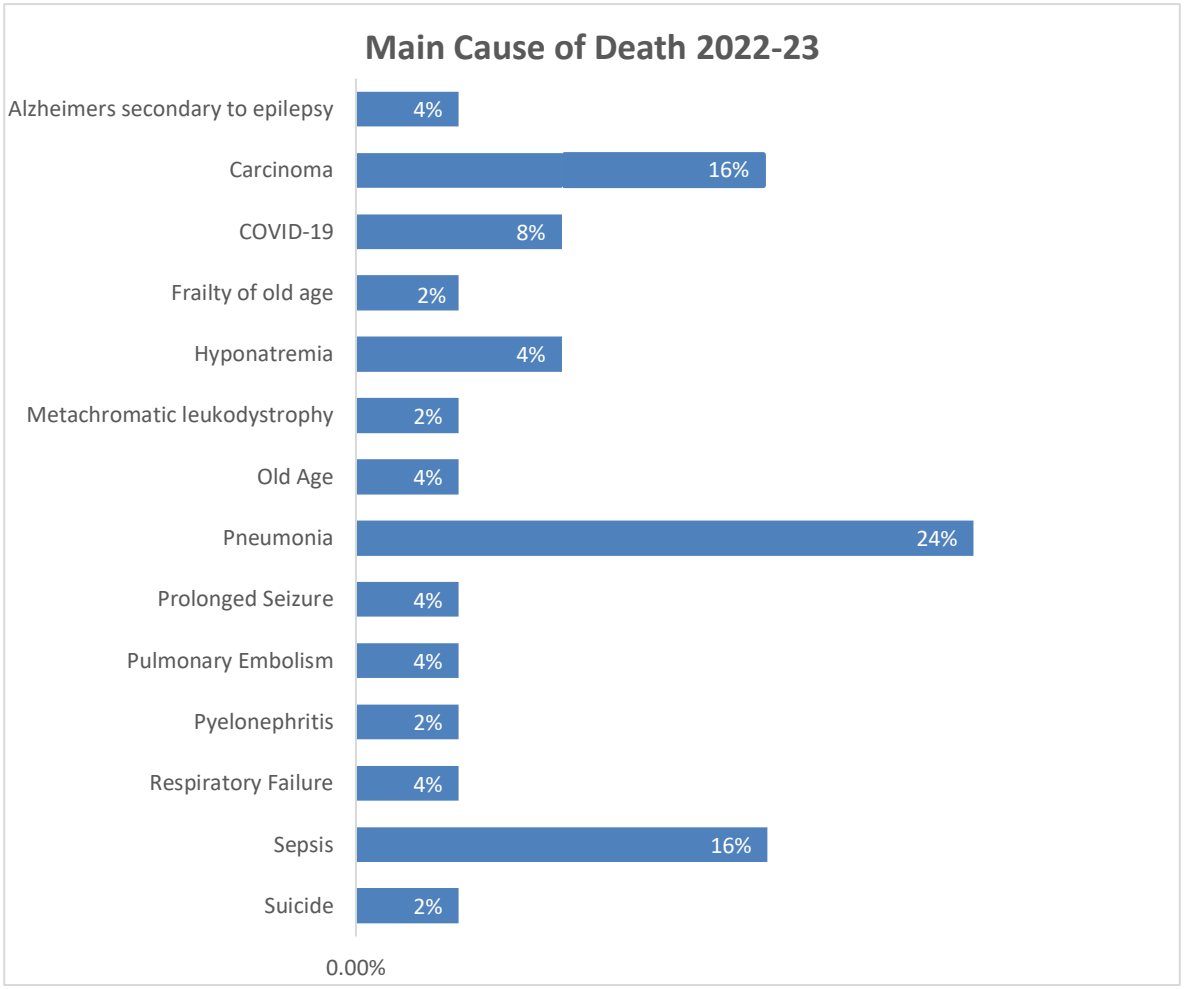
The reviewer records the cause of death in the review as detailed on the person's death certificate. From the completed reviews, 23% of deaths were related to pneumonia as the primary cause.

Reviews identified that a small number of death certificates state, 'learning disability' or 'Down's Syndrome' as a secondary cause of death. This has been discussed with the medical examiners to ensure appropriate guidance is given to clinicians about not using this incorrectly as a cause. We have also raised this issue with providers to address in learning disability awareness training for medical staff.

Graph 10: Covid Deaths



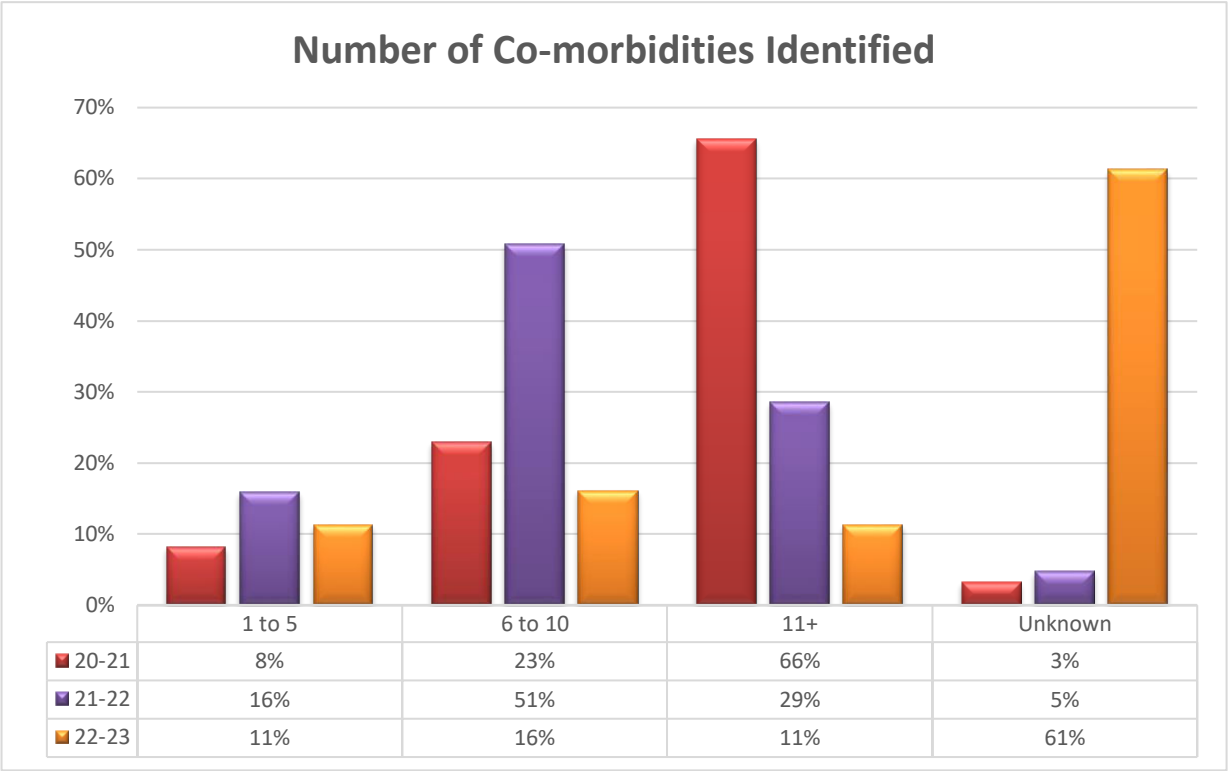
Graph 11: Main causes of death



Graph 9 - Number of co-morbidities

Every person in the reviews had one or more co-morbidities. However the design of the new national forms does not ask reviewers to detail co-morbidities in the review. This has made it difficult this year to collect comparison data on co-morbidities with 61% of reviews unknown. The highest number of co-morbidities for one individual was 11.

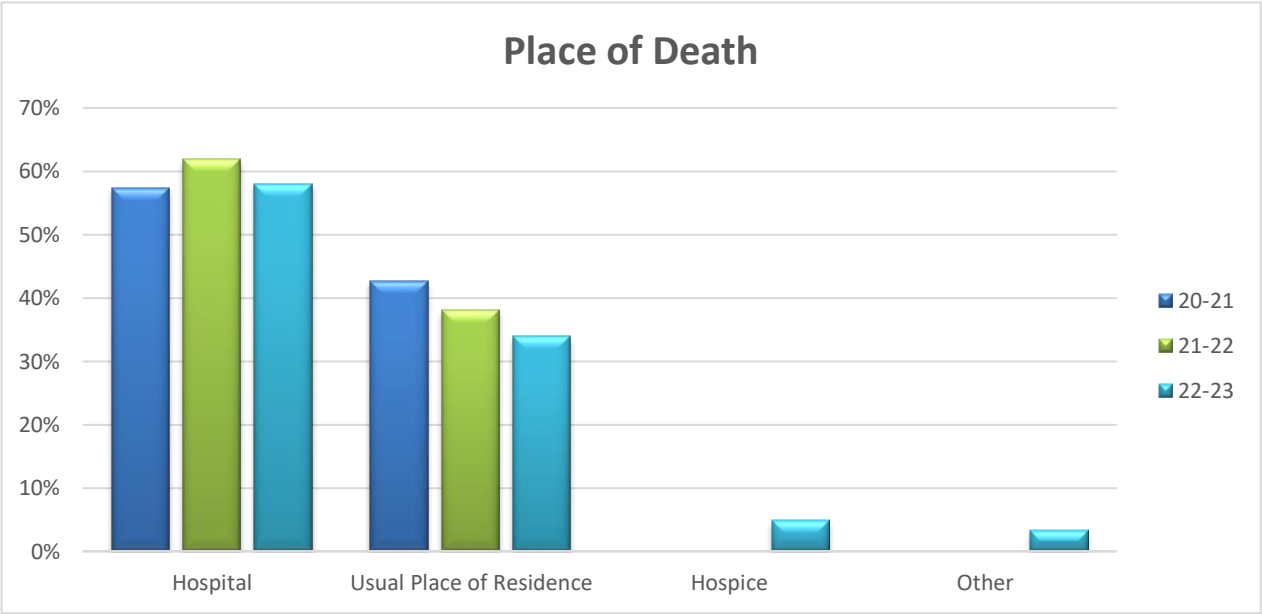
In the older age group some co-morbidities were due to age. There was a high incidence of diabetes, epilepsy, obesity, heart disease and cancer.



	1 to 5	6 to 10	11+	Unknown
20-21	8%	23%	66%	3%
21-22	16%	51%	29%	5%
22-23	11%	16%	11%	61%

Graph 10 shows the place of death for cases reported in 2022/23. For BNSSG 59% of deaths occurred in hospital. There has been a decrease in the numbers of people supported to die at home but a noticeable effort this year where people were on End of Life care and residential staff had to make special arrangements for the person to die at home with friends and family with some very positive practice. Also a 5% of people were supported by a Hospice which is new this year, and linked to the number of people dying of cancer.

Graph 10: Place of death



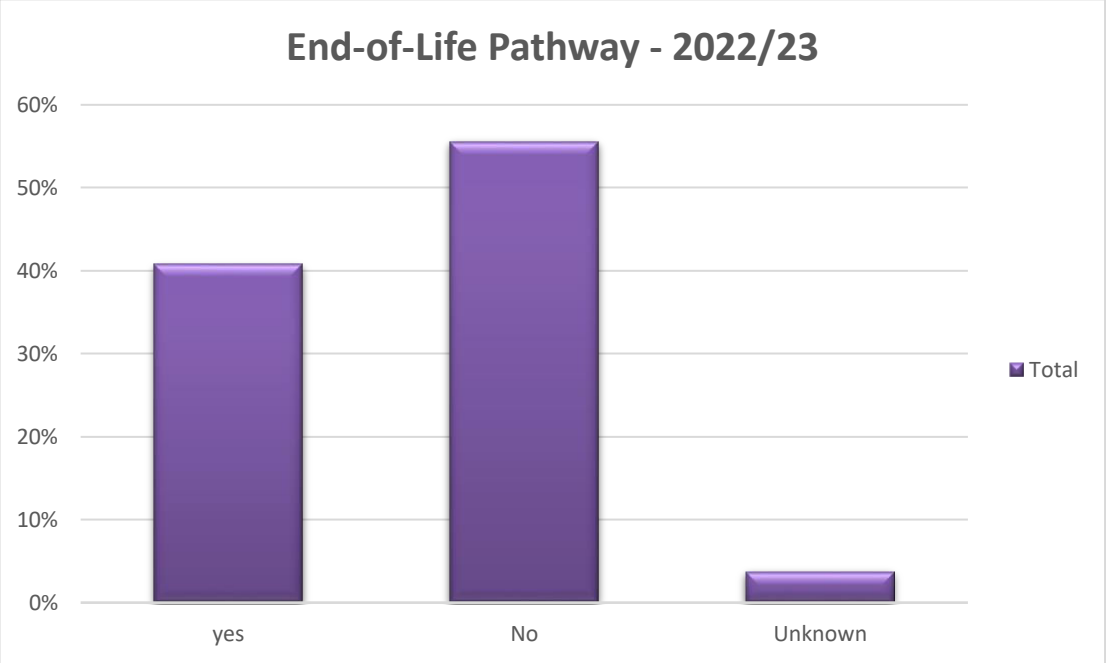
An individual's choice for their place of death is taken into account and usually documented through ReSPECT forms which we have seen used much more this year either with care home staff or through support of the learning disability liaison nurses in hospital. Sometimes Mental Capacity Assessments or Best Interests meetings are used. There has been some involvement of specialist bereavement services and staff in hospices supporting End of Life care.

End of Life

Within the reviews we look to identify if End of Life care planning was in place for those where death was expected. The following graph shows that this was the case for 41% of the reviews, a slight increase on last year.

There has been more evidence of End of Life discussions taking place with the person themselves this year before their death and involving family members in those discussions. We have had some lovely examples of people planning their own funerals, with songs, poems, special requests and involving animals and family pets. Several people now have had a horse drawn hearse at their funeral which is a popluar choice.

Graph 11: End of Life care pathway

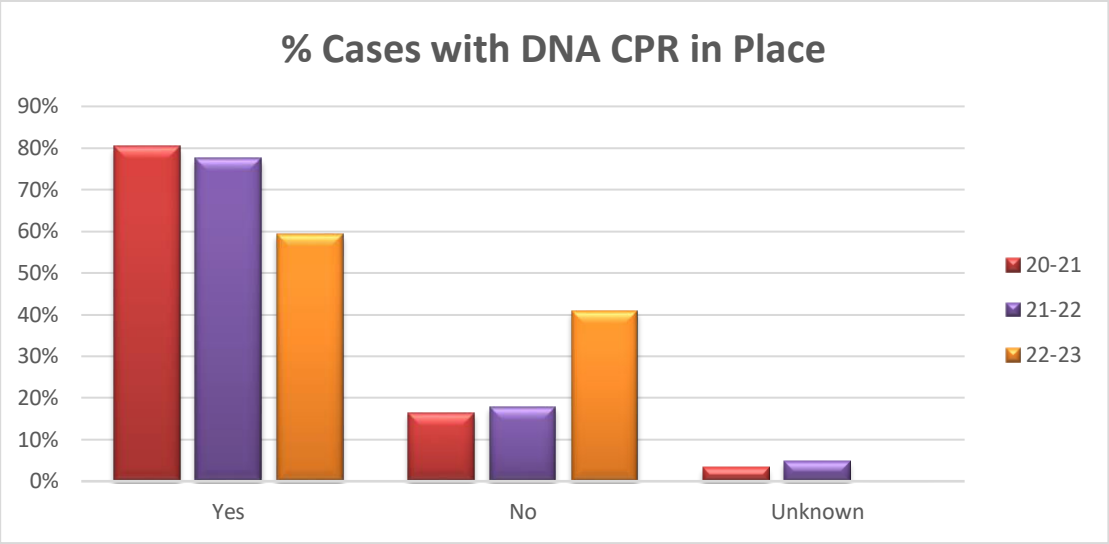


Support for End of Life Care:

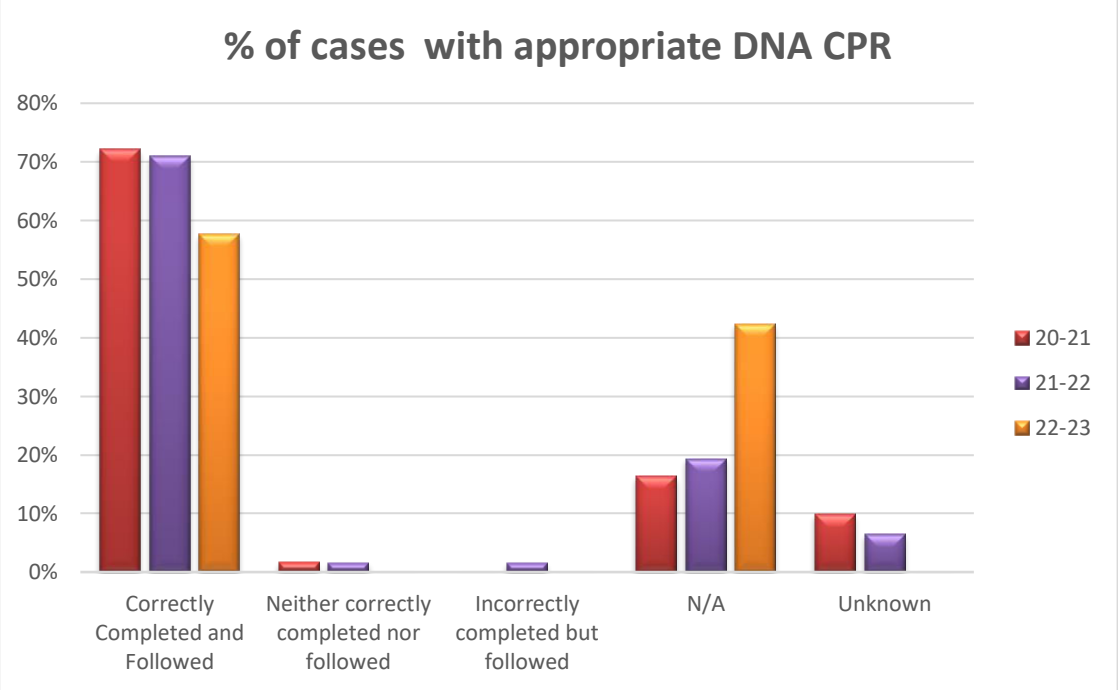
Across residential and support services staff are passionate about the people they supported, wanting to ensure that they were able to continue to support them throughout their life, including at the end. Most homes had no training in providing end of life care even though they were supporting older adults, some of whom had experienced a decline in health and the care staff did not have time to access additional training. Several services sourced bereavement support through St Peters Hospice, which staff were given dedicated time to access.

In addition reviews look to see if a 'Do Not Attempt Cardio-Pulmonary Resuscitation' order was in place. The following graph shows that for 59% of the reviews this was the case.

Graph 14: DNA CPR in Place



Graph 15: Reviews with appropriate DNA CPR



Of the reviews where a DNA CPR order was in place the reviewers noted that 58% were appropriate, correctly completed. For 5% of cases paperwork was not available to the reviewers to assess the completion. The reviewer assesses appropriateness and looks for Mental Capacity Assessments, Best Interest meetings and involvement of next of kin or an Independent Mental Capacity Assessor (IMCA).

Our providers undertook and audit of ReSPECT forms for people with learning disabilities in hospital. At NBT 100 sets of active case notes were audited and the reasons for a DNA CPR assessed. 35% of cases had a DNACPR in place. In 11% of cases Learning Disability was identified as the sole reason for DNAR, with 35% having LD as the part of the rationale for DNACPR. 27% had family involvement in the decision. The Trust has taken action with teaching for junior doctors and raising awareness with the Consultant body led by the Chief Medical Officer. Findings and required actions shared with ReSPECT leads across all specialties and presented at regional meetings to raise awareness and share good practice.

Annual Health Checks

In previous years evidence of completion of Annual Health Checks (AHC) for people with learning disabilities in completed mortality reviews was generally low, particularly finding the documentation to review the Annual Health Check discussion and any agreed health action plan goals. We have worked closely with GP practices to improve completion rates over the last two years. We understand the importance of the AHC in keeping people with learning disabilities in optimum health, therefore we undertook specific work to address this over the year and look at how we could better support GP's and practice staff to complete AHC's.

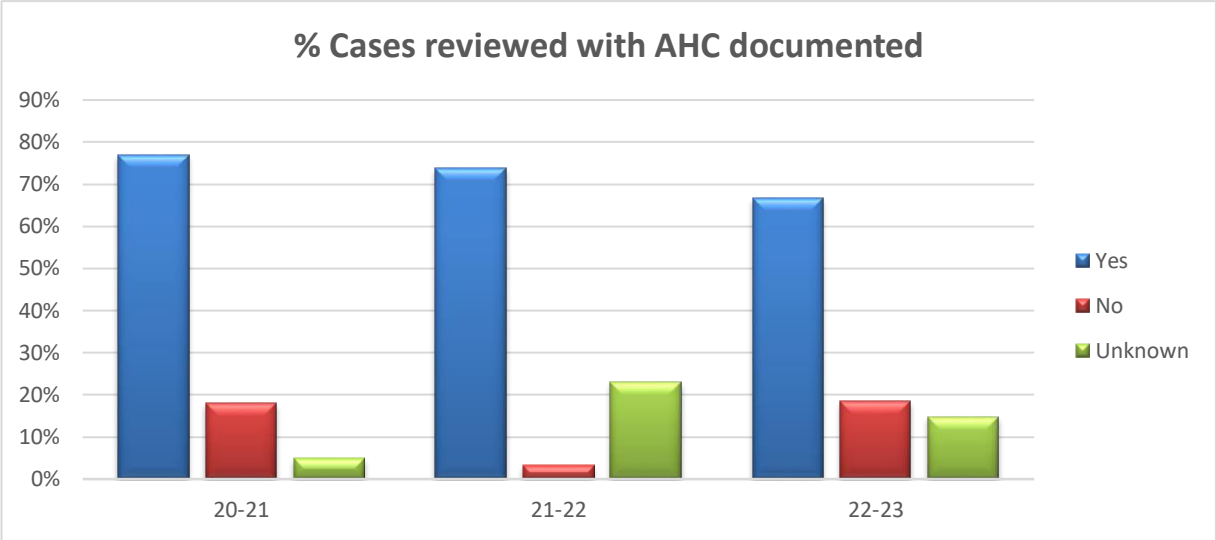
In 2020/21 we established a lead Learning Disability GP's contact list in every practice to establish a BNSSG Learning Disability lead GP Forum. We then developed a series of webinars for GP's and practice nurses on AHC's. Further quarterly webinars were held this year on cancer screening, constipation, obesity and autism. These are well attended by practice staff, (40+ staff) and recorded for those who cannot attend.

We continued to develop a toolkit of AHC resources to support GPs & practices, validated by Community Learning Disability Teams on the AHC portals hosted on GP platforms – Teamnet/Remedy, including easy read resources on a range of topics.

We have been especially proud of the work undertaken by our GP and primary care colleagues this year, who have ensured people with learning disabilities have an Annual Health Check. This is key to ensure people's long-term health conditions are well managed

and GP's agree health goals with their patients. The majority of our GP's exceeded the target achieving 82% of completed annual health check for the patients with a learning disability on their register. With 98% of those having a Health Action Plan (last year 54%) 24% of practices completed100% of their Annual Health Checks. That's over 4,000 people with learning disabilities who have had an Annual Health Check this year across BNSSG.

Graph 15: Completion of Annual Health Check evidence in reviews



From completed reviews not all document in the narrative whether an Annual Health Check has taken place. This is in part due to the tick box design of the LeDeR Initial review forms requiring an exact date. However from our close monitoring of Annual Health Checks of all learning disabled patients on GP registers we are confident of the completion of these across BNSSG.

Section Five – Learning from reviews

Learning from local reviews - Quality Assurance Review Panel identified themes

From an overview of completed local reviews during 2022/23, the Quality Assurance Review Panel has identified a number of recurring themes. These focus on areas where improvements can be made to improve the health and social care for people with learning disabilities. There is usually more than one theme per review.

Table 6: Recurring themes

Learning theme	Number of LeDeR reviews where identified
Constipation	39
Obesity	33
Aspiration pneumonia	31
Catheter Care	7
Reasonable adjustments	33
Mental Capacity Assessments, Best interest meetings	38
Cancer – late diagnosis	26

The Quality Assurance Review Panel noted many areas of good practice including:

- Regular support staff continuing to visit the person whilst they were in hospital.
- Best interest decision-making meetings involving family or an IMCA
- Primary care carrying out comprehensive patient reviews involving CLDT's and residential staff
- GPs and practice nurses undertaking home visits and ward visits
- Multi-disciplinary meetings in hospital to review full care of the person, including physical health, cognitive and behavioural needs.

Examples of best practice;

- People with learning disabilities having a clear easy read hospital passport that is fully completed and up to date by residential staff
- Innovative reasonable adjustments such as meeting a young man in his parents care to take blood
- 'Grab sheets' with key health and communication information kept on the person's bedroom door for ambulance staff
- Bereavement support for residents and staff when they lose a friend they had lived with for 30 years
- Top up packages for people in residential homes to support changing healthcare needs as people age, ensuring people are not moved unnecessarily from their homes of 25+ years in the last year of their life.

Actions taken to address themes identified

Annual Health Check

Every person with learning disability on a GP register should be invited for an Annual Heath Check (AHC) by their GP, supported where required by community providers. Following the AHC, each person should be given a Health Action Plan (HAP) by their GP. This is a summary of the discussions and the health goals agreed for the person to work on with their carers or support staff.

There are a considerable number of people in supported living or with families who miss out on AHC. We worked with the Brandon Theatre Group – actors with learning disabilities to produce a video about the Annual Health Check. This was sent to all GP practices to use with patients to remind patients to book their AHC. This promoted AHCs and empowered to people to have better understanding of an annual health check, why they are important for keeping healthy and help people to ask their GP about their personal health goals.

The video was fantastic and even had a very catchy song. It was launched in September 2022 timed for quarters 3 and 4 when most GP practices carry out Annual Health Checks.

https://www.youtube.com/watch?v=dGITBtSSEGo

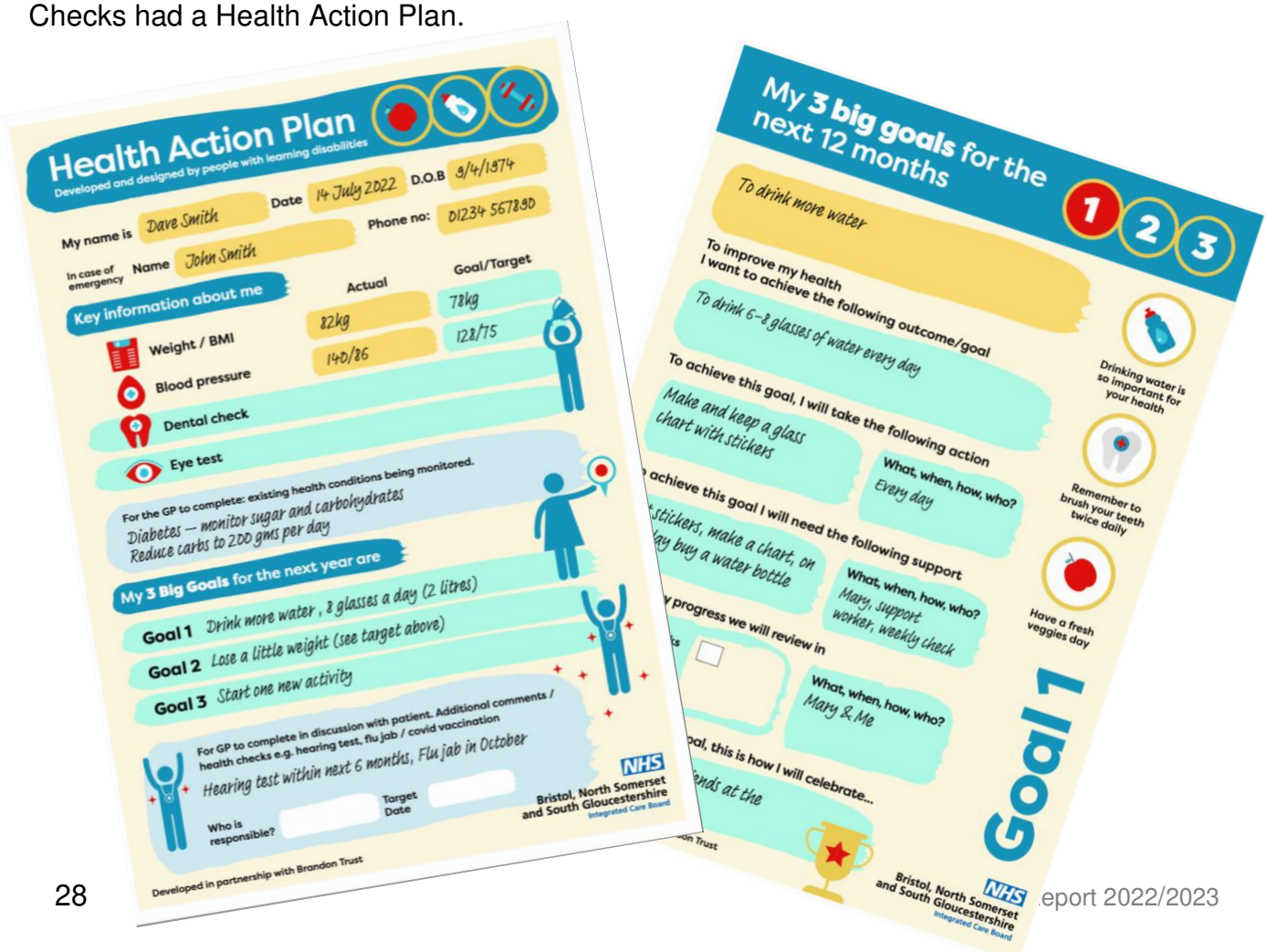
Improving uptake of Annual Health Checks

Our GP's have met the national target for three consecutive years. We have proactively supported our GP colleagues in primary care to ensure people with learning disabilities have an AHC. We supported our GP practices through various work such as;

- AHC video developed with learning disabled actors for GPs to send to patients as a reminder
- Developed and designed Easyread Health Action Plan with learning disabled people.
- Keeping our easy access intranets for GP's (on Remedy & Teamnet) up to date with new resources to support best practice, provide easy read templates, leaflets of patients & carers on key topics
- providing quarterly webinars on key topics such as AHC, hearing/eye sight & oral health at part of AHC, autism, epilepsy, sexual health and transition from paediatrics
- AHC training events for Practice Nurses and administrators to support practices to achieve the target.
- A regular GP newsletter on learning disability issues.

Health Action Plans

Last year (2021/22) 53% of AHCs did not result in a Health Action Plan - the health goals the GP agrees with their patient. This diminishes the likelihood of health improvement in the patient. We commissioned Brandon Engagement Group – a forum of people learning disabilities to co-produce the Health Action Plan with us. They developed an easy read template to capture the required elements of a HAP. The final design was distributed to all BNSSG practices to use with patients. It was also developed as an EMIS template, so it auto populates patient details. This year the achievement was 98% of all Annual Health Checks had a Health Action Plan.



Constipation

From the reviews undertaken in 21/22 80% people reviewed had an issue with constipation, some very severely, with impacted bowels that resulted in sepsis. This continues to be an issue in the 2022/23 reviews.

We commissioned a co-produced project with North Somerset People First called “Poo Matters”, led by a senior learning disability nurse from Sirona Care and Health. The group explored issues about constipation and found out peoples’ experience. Group members said they didn’t know what constipation was and would be too embarrassed to talk about poo with their GP. One person thought it was normal to only poo once every three weeks.

The project worked through lockdown using Zoom sessions for discussions and remote cookery. The group developed recipes to improve diet and to test and a ‘sweetcorn challenge’ to help learn how quickly your bowels moved. Recipes including constipation cookies, celeriac mash, apples stuffed with dates and Weetabix cake. This work has continued with new members.

They also developed and delivered co-produced a constipation pilot training programme for 40 carers. We have continued to commission this project with North Somerset People First and expand the training offer across BNSSG with a resource pack which will include details on how to access the educational tools, easy read resources, recipe cards and training for carers and families raising awareness about constipation and how to address it.

The Poo Matters Team presented at the National Learning Disability Conference in 2023 running a workshop, meeting leaders at NHSE, demonstrating their constipation resources and showing everyone how it’s done at 70’s night!

Obesity

A growing number of reported deaths have a BMI over 30. This has increased during lockdown with people eating poorly and taking little exercise. We held a webinar with GP's on obesity and constipation including information from dieticians, service users and social prescribing in December attended by 48 GP's.

Our 'Healthy Me' cookery school has addressed obesity and diet for people with learning disabilities in partnership with Square Food Foundation and housing/support providers, Milestones and Brandon. We wanted to encourage people to make connections between what they eat and their health. Ther first students began the 12 week course in April 2022. The learning was intended to be more sustainable by teaching learning disabled people themselves to cook and take an active role in decisions about their meals and snacks.

Participants selected had difficulties with their weight and completed before and after food diaries. It included on-line homework, 'come dine with me' social element to invite friends & family to dinner, training & recipe kits each week for students to take home. Also a session was held for managers outlining the importance of healthy, wholesome foods and the link to people's health.

All recipes developed were low fat, teaching people about how to sweeten dishes without the use of sugar. Learning about how quick and easy it easy to produce home made wholesome dishes. Popular recipes were beetroot muffins and courgette pizza.

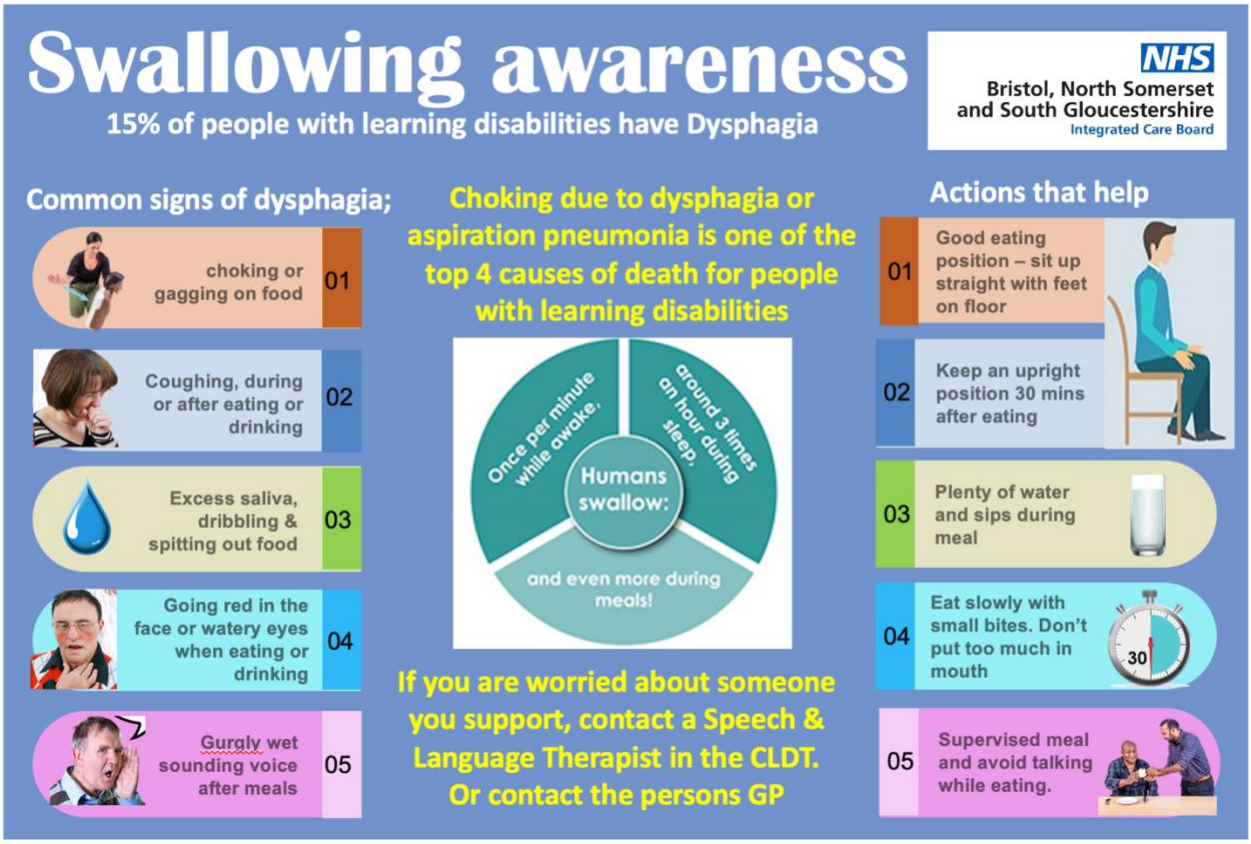
Through the use of the kitchen garden we also linked to gardening projects growing herbs & vegetables in the home to supplement diets. Participants are taking an active role in decisions about their meals and snacks - those on the two completed cohorts have changed eating habits and lost weight. The third course began in March 2023, with over 45 participants having completed the course and receiving their certificates.

Aspiration Pneumonia

Our top cause of death in LeDeR reviews. We developed a choking flier with Speech and Language Therapists, raising awareness in residential settings to reduce the risks of people aspirating, sent to over 400 homes.

In BNSSG we are working with providers to set up training/awareness groups for people with learning disabilities who have dysphagia so people can understand their own condition. The service user group is looking at making meals appetising working with Square Food Foundation, and developing tastier recipes and meal presentation sessions for providers Cooks.

We contributed to a regional group developing dysphagia guidelines. We hope to set up an equipment library to support families and residential services to be able to try aids and adaptations to see if they are suitable for their family member/clients to reduce incidence of choking.

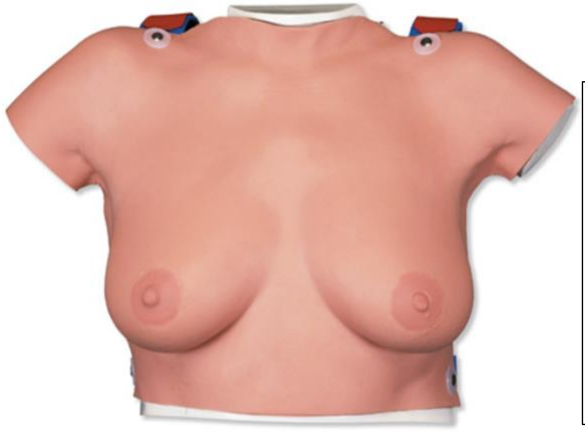


Cancer Screening and Treatment Access

Reviewers check that people with learning disabilities have been invited and supported to attend screening appointments. National programmes are for Bowel, Breast and Cervical screening. The evidence in reviews is mixed - some people are supported very well to attend screening appointments. However there are documented in some GP notes, where a decision has been made that the person 'will not tolerate screening'. This is often assumed without any consideration of reasonable adjustments nor as part of a Best Interests meeting.

HHS Digital breast screening data for there is a 15% difference between women with learning disabilities attending a screening appointment compared to women in the general population in England. 34% of eligible women with learning disabilities attend cervical screening compared to 75% of women without learning disabilities. Colorectal screening is closer to the uptake for the general population but the test is less invasive.

We held a cancer screening webinar in June attended by 68 GP's covering reasonable adjustments and other support. We provided guidance to GP's on 'supporting people with LD who have cancer' developed with providers and Cancer Research UK. We are working with screening colleagues to provide dedicated screening days



Wearable breast tabard

NHSE has funded a permanent screening practitioner to improve the uptake for people with learning disabilities. This post will be based in Sirona and we are currently developing Job Description and a workplan for the next three years. The aim of the Screening Practitioner role for people with learning disabilities is to:

- 'Increase screening uptake in people with learning disabilities to levels similar to those in people without learning disabilities for each adult national screening programme. With the intension of reducing the morbidity and mortality related to the disease or conditions screened for by the adult national screening programmes.'

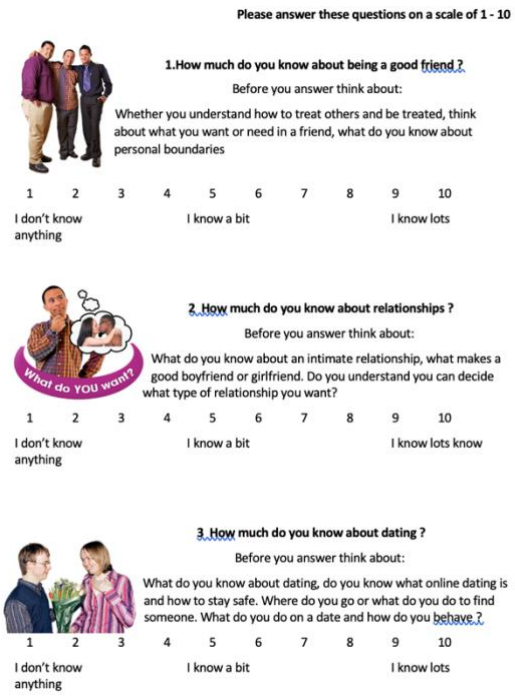
- Scope for the Learning Disability Screening Practitioner is the 5 adult screening programmes: Abdominal Aortic Aneurysm (AAA) Screening, Diabetic Eye Screening, Breast Cancer Screening, Bowel Cancer Screening and Cervical Cancer Screening.

We want people with learning disabilities to be supported to understand their own bodies, participate fully in cancer screening programmes, and hopefully detect cancers at an early stage so people can access cancer treatment. Breast and testicular examination is problematic for carers as they cannot easily lay hands on a person without risking allegations of inappropriateness. We have sourced a range of anatomically correct breasts, chests and testicles with lumps, dimpled skin and other cancer indicators that can be held against the person with learning disabilities body to teach self-examination.

In regard to treatment access – we have a concern that people with learning disabilities who are diagnosed with cancer are not receiving equal access to chemotherapy and radiotherapy. Our Business Intelligence team is exploring 10 years of data to review this. Acute providers are keen to explore this with us and address any potential concerns in the Health Providers Network.

Relationships and Sexual Health

There has been an increase in unplanned pregnancies with younger people, especially those who live independently. People with learning disabilities have the right to receive information about their sexuality and relationships in a way they understand. With the increase of on-line activities and dating, people with learning disabilities are vulnerable to those who target and exploit them in the mistaken experience that friendships or relationships are being offered.



Please answer these questions on a scale of 1 - 10

1.How much do you know about being a good friend ?

Before you answer think about:

Whether you understand how to treat others and be treated, think about what you want or need in a friend, what do you know about personal boundaries

1 2 3 4 5 6 7 8 9 10

I don't know anything — I know a bit — I know lots

2. How much do you know about relationships ?

Before you answer think about:

What do you know about an intimate relationship, what makes a good boyfriend or girlfriend. Do you understand you can decide what type of relationship you want?

1 2 3 4 5 6 7 8 9 10

I don't know anything — I know a bit — I know lots know

3. How much do you know about dating ?

Before you answer think about:

What do you know about dating, do you know what online dating is and how to stay safe. Where do you go or what do you do to find someone. What do you do on a date and how do you behave ?

1 2 3 4 5 6 7 8 9 10

I don't know anything — I know a bit — I know lots

The Hive Avon

Relationships Matter @ The Hive

Who is the training for?

- Adults (over 18) with a learning disability and/or autism, who wish to know more about relationships and how to enjoy a healthy safe sex life.
- Participants do not need to be in a relationship or to have had a relationship in the past.
- Participants must have the mental capacity to understand and consent to having a relationship.
- This is a mixed gender training course for 12 people therefore if people find it difficult or upsetting to talk about relationships and sex then this course will not be suitable for them.
- Participants should be able to communicate with others in a group setting and ideally be able to read and write, albeit a little, HOWEVER this is not essential.

We are unable to provide 1-2-1 support, individual therapy, or counselling therefore, if participants have experienced past trauma/abuse this course will not be suitable for them.

If you're unsure whether the course is suitable, please contact Dominic Box at The Hive BEFOE APPLYING.

Course content

1. Healthy relationships - What does it mean to be a friend and how to treat one another. We will look at the different types of relationships and how our behaviour differs depending on the type of relationship. We will also talk about personal boundaries and appropriate behaviour.

2. Intimate relationship - We will talk about the choices people have around the type of relationship they want. We will discuss relationship rules, what they are looking for in a relationship and how they should expect to be treated.

3. Healthy dating - What is dating and how to be safe when dating, what is online dating the do's and don'ts and how to be safe online. Where do you find someone, what do you do on a date and how you should behave?

4. My body - We will learn about both male and female sexual body parts, what they are called and what they do. We will learn about how your body works and how you can enjoy your body. What is body image and how to feel good about yourself.

5. Sex - What is it? - Not all intimate relationships will involve having sex; it's all about choice. We will discuss being ready for sex and not feeling pressured, about sex including foreplay, the different ways to be intimate, different sexual positions and how to enjoy each other's bodies.

6. Sexual Health - We will talk about what safe sex is, we will discuss how to have sex safely preventing pregnancy or catching an STI. We will talk about the different forms of contraception. We will also talk about how to check your body to stay healthy.

7. Consent - What is consent and why is it important? What is the importance of giving AND getting consent before you have sex, what does the Law say about sex? Do you know how to say no if you don't want sex?

8. Unhealthy relationships – Do you understand how your boyfriend or girlfriend should treat you? Do you understand what domestic and sexual abuse is and how to stay safe? What to do if you think you are in an unhealthy relationship.

More people with learning disabilities are at risk of being exploited through inappropriate or unwanted sexual relationships. The potential risk for unplanned or unwanted pregnancies and sexual and financial abuse is increased.

We commissioned The Hive to provide co-produced training led & presented by people with learning disabilities with educational materials to support families, staff & services. Offering places for people with learning disabilities across BNSSG.

Independent Living Skills

Many people with learning disabilities across BNSSG live with their parents, many of whom are becoming elderly and may not be able to care for their son's and daughters in the longer term. The Hive works very closely with parents through their Building Independent Lives Together (BuILT) project. The aim is to work with adults and their families to enable people to live more independent lives

The Hive provides Independent Living Skills and Live Skills training designed to give participants the skills, knowledge and confidence to transition to independent living. BNSSG has funded the The Hive to provide a series of news courses.

The Hive Avon

Independent living skills training course for autistic adults and adults with learning disabilities.

Learn about safety at home and when you're out, personal hygiene and health, healthy eating, kitchen hygiene, living on a budget, banking, money safety and more

This is a 6-session course and the dates are:

Tuesday	30th May	1.30pm – 4 pm
Tuesday	6th June	1.30pm – 4 pm
Tuesday	13th June	1.30pm – 4 pm
Tuesday	20th June	1.30pm – 4 pm
Tuesday	27th June	1.30pm – 4 pm
Tuesday	4th July	1.30pm – 4 pm

To book a place you will need to fill in an application form and pay a fee of £30

To get an application form or for more information contact Dominic on 0117 9614372 or dominic.box@thehiveavon.org.uk

Funded by BNSSG ICB NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board

The Hive Avon Limited, 322 Two Mile Hill Road, Kingswood, Bristol, BS15 1AJ

Section 6 - Involving people with learning disabilities and autistic people in our work

Every health improvement project we have developed this year has been co-produced with people who have learning disabilities or autistic people.

Autism Audit of Emergency Departments

We completed user-led audits of all four BNSSG emergency departments using a re-designed the audit tool. These whole day audits carried out by autistic people include evaluating the department for access, adaptations, and interviewing key staff for their understanding of autism. Individual reports and recommendations were completed and sent, tailored to each specific ED.

We started with an audit tool recommended by NICE – people in the team felt this was out of date, used patronising language and was not developed by autistic people. We re-designed the audit tool and have audited 4 hospital EDs. Recommendations were made to each ED and hospital with further developments such as purchasing reasonable adjustment resources and training.

We were shortlisted for the National Patient Engagement Awards for this work producing a video with the autistic team who carried out the audits and poster display for the nomination. Pictured right are two of the team who accepted the runners up award in Birmingham in November 2022.

Co-produced Autism Training for ED staff

Following the audits we developed autism training for ED staff across system. Four short webinars of 45 minutes for ED staff across BNSSG were delivered, with scenarios and Q&A. Autistic people were co-trainers and paid accordingly on an experts-by-experience rate. Sessions were timed for morning handover and tailored for Emergency Department staff. We developed an 'experts by experience' component to the training where service users with autism shared stories and experiences of using emergency services. Over 80 ED staff attended the sessions delivered in September and October 2022.

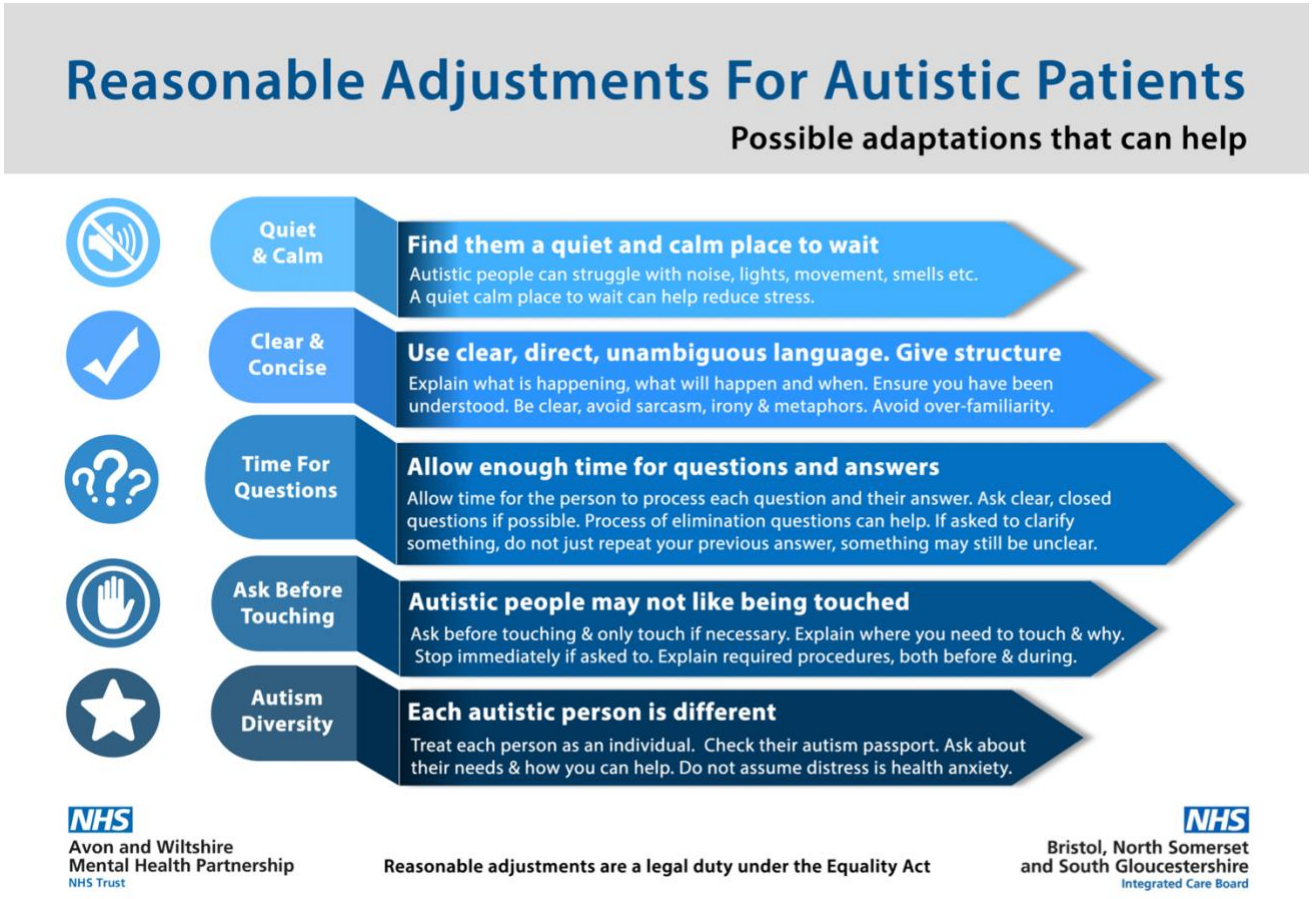
Autism - Question Time.

We have worked with Bristol City Council and Diverse to develop BNSSG/ICS wide events. These will be flexible to incorporate a range of opportunities for autistic people to have a voice. It will be an on-line meeting with an open invite rather than fixed membership.

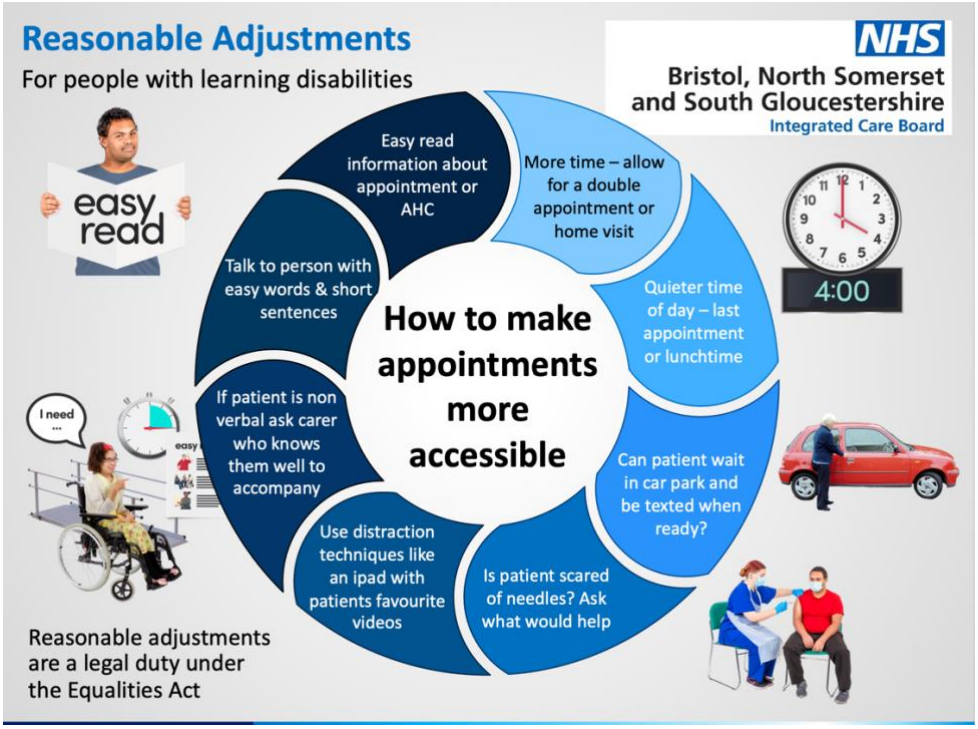
Similar to 'Question Time' events, meetings will be held 2-3 times a year, for autistic people to meet leaders of health organisations, city councils etc. Meetings will be themed on issues such as hospital access, support from GP's, transport, police, etc where people with lived experience can share their story or contribute to discussions from their perspective. Autistic people can dial in, camera on or off, contribute via the chat function or send email points in advance. The programme and events will be organised by Diverse based on feedback from autistic people.

Reasonable adjustments - guidance

Through the ED audits undertaken by autistic people the group produced an autism flier for staff which had 5 top tips for supporting autistic people who come to the Emergency Department. People in the group had experiences being treated in ways which exascerbated stress level especially when people were unwell. The purpose of the guidance was to give staff a guidance on the best ways to support & approach an autistic person. This was distributed through matrons on all hospital sites.



Reasonable adjustments guidance developed by people with learning disabilities for GP appointments. Sent to all learning disability lead GP's in every BNSSG practice.



Reasonable adjustments – resources

We also identified recommendations to expand the availability of reasonable adjustment resources for autistic people and for people with learning disabilities across all the hospital sites. These will be made available in a wide range of clinical areas to support people's access needs and promote a calming environment for example; ear defenders, soothing lights and smells, 'fidgets', weighted blankets/lap pads, dark glasses or visors for light sensitivity, augmented alternative communication boards, images bed projectors

BNSSG have funded 25k to purchase reasonable adjustment resources to be made available in all four hospitals, emergency departments and a wide range of clinical areas to support people's access needs and promote a calming environment.

Training programme to identify deteriorating health in people with learning disabilities.

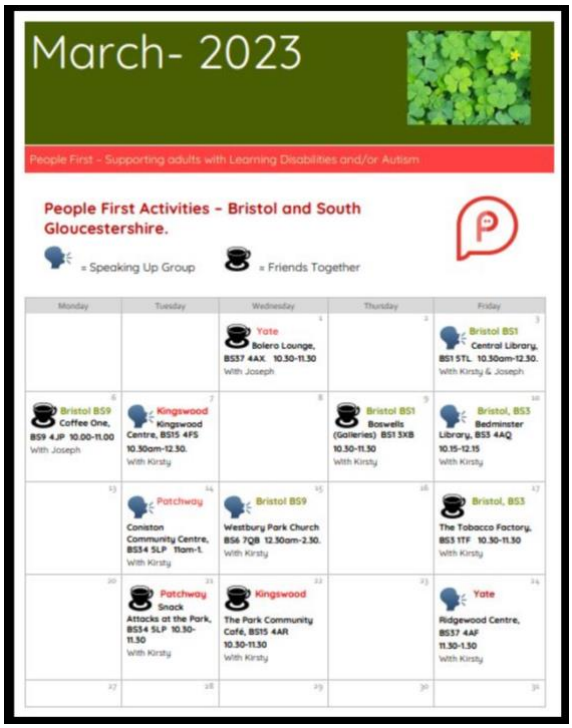
We funded a series of bite size sessions for support staff at Milestones – that were aimed primarily at new and less experienced staff in housing and support providers working in residential settings. These gave staff a solid foundation on how to support people with their health in proactive way. This was particularly important as we came out of the pandemic where housing and support providers have recruited many staff new to caring for people with learning disabilities and often have no clinical skills or training. These sessions prepare new staff to look out for signs and symptons that people with learning disabilities may be becoming unwell.

Examples of training are;

- Supporting people with intimate care needs. Supporting with dignity but also using this time to make observations that might alert staff to signs of ill health.
- How to recognise when someone is unwell (soft signs – as a precursor to Restore2 for new staff)
- Health Inequalities – Why people with LD die younger and what we can do to change this
- Health Screening – what screening people should have, how to prepare and attend appointments

Rebuilding self-advocacy across BNSSG/ICS

Ensuring people with learning disabilities have voice and influence is a key ambition in our system strategy. It requires commitment and funding to build systems for people with learning disabilities to be equal partners in our different work streams. Currently there is little or no involvement of people with learning disabilities in key meetings about learning disabilities. The pan disability model has not been successful in representing or bringing the voices of people with learning disabilities to the table.



We have funded North Somerset People First for three years to expand People First groups across BNSSG. Work commenced in April 2022. There are 12 new groups across Bristol and South Gloucestershire every month.

- Walk and Talk
- Friendship Cafes
- Womens wellness
- Men's Wellbeing
- People First speaking up

14 existing monthly groups in North Somerset

- Speaking up Weston
- Friends Together
- Womens wellness
- Men's Wellbeing
- Young People - Empowering Voices
- Litter pickers

We hosted a two day event in November bringing North Somerset People First together with Merseyside People First - another group who have been running for 30 years. They have been working on a lot of health issues, including death and dying, blood tests & needle phobias, The David Project on grief and bereavement, working with the police on bullying and harassment They were also working with Photosymbols developing new symbols on death and dying.

We wanted to bring the groups together to build a community of national practice. Self advocates can see what issues are being addressed across the country. This supports local self advocates to develop their skills of leadership.

By building foundations and self- advocacy skills amongst people with learning disabilities we are supporting people with lived experience to have a voice. By developing opportunities to speak up and work with us on co-production across a range of work programmes we are building support for people to speak up for themselves. Elected members and self-advocates with learning disabilities who have 20+ years of experience of speaking up have been leading the projects.

Section Seven - Summary

This is the fourth Learning Disability Mortality Review (LeDeR) annual report for Bristol, North Somerset and South Gloucestershire ICB. The report provides the detail of how the LeDeR process has been implemented, demonstrating how our governance arrangements support a robust approach to learning from the deaths of people with learning disabilities.

As we developed into an Integrated Care system (ICS) over this past year we are passionately committed to keep learning as a result of LeDeR reviews and continue to drive an innovative work programme that makes changes to improve services and address health inequalities experienced by people with learning disabilities.

Action Learning

LeDeR reviews provide regular information on the themes and recommendations identified from mortality reviews and this informs and inspires our programme of work. This year every health improvement project we have developed has been co-produced with people who have learning disabilities or autistic people.

Some of the agreed priorities identified for health will be progressed as part of the Learning Disability Health Providers Network work plan that reports to the Learning Disability and Autism Programme Board.

Bristol, North Somerset and South Gloucestershire
Integrated Care Board

Meeting of BNSSG ICB Board

Date: Thursday 6th July 2023
Time: 0900-1500
Location: MST

Agenda Number:	6.3	
Title:	This report is to update the BNSSG Integrated Care Board on the outcome of the assurance report commissioned by NHS England in November 2021.	
Confidential Papers	**Commercially Sensitive**	No
	Legally Sensitive	No
	Contains Patient Identifiable data	No
	Financially Sensitive	No
	Time Sensitive – not for public release at this time	No
	Other (Please state)	No

Purpose: Approval/Assurance/Information

To provide Board with an update on the "Assurance Review of the implementation of recommendations following the independent review of the LeDeR process for Oliver Thomas McGowan". This review was commissioned by Claire Murdoch, National Director of Mental Health NHS England to provide assurance that BNSSG ICB (formerly BNSSG CCG) had made sufficient progress with the recommendations of the "Independent Review into Thomas Oliver McGowan's LeDeR Process Phase two" which was conducted by Fiona Ritchie and published in October 2020.

Key Points for Discussion:

The "Independent Review into Oliver McGowan's LeDeR Process phase two", was published in October 2020 and presented to Governing Body in November 2020 along with the Second Multi-Agency Review (MAR) into his care. The basis of the review was to identify where specific improvements could be made in the quality assurance processes of LeDeR in BNSSG. The phase two review made a total of 21 recommendations in total, 11 of which were for for BNSSG, each relating to specific areas of learning, the independent review panel also suggested several improvements that could be made. System work with providers and partners has been undertaken to address all the recommendations in the LeDeR Review and second MAR throughout 2020/21 and improvement work is ongoing including a programme of co-production to address themes emerging from the LeDeR programme and to address health inequalities and access for this population group.

In order to provide assurance that our system had made sufficient progress with the recommendations of the independent review Claire Murdoch, National Director of Mental Health NHS England commissioned David Harling, National Deputy Director for Learning Disability Nursing, to undertake an Independent Assurance Review in November 2021. The review included two parts - a quality assurance methodology to assess evidence provided to demonstrate completion. Over 200 separate documents were provided as evidence as part of the first stage of the review.

The second stage focussed on how improvements were being delivered in practice, using a quality-checking methodology, these were carried out by two independent face-to-face quality checks. This engaged people with lived experience to check the progress of the recommendations in practice at Southmead hospital and for the review lead to observe directly how the local system was working to improve the lives of people with learning disabilities and autistic people. Stage two included a two-day programme of site visits to BNSSG, focus group discussions with system partners and a site visit to North Bristol NHS Trust, Southmead. This was to hear presentations from the Independent Quality Checkers with learning disabilities from Brandon Trust and the Emergency Department Autism Audit carried out by autistic people from BASS.

David Harling's report concluded from the culmination of the findings for both stage one and stage two of this assurance review, it is evident that BNSSG ICB has actively implemented all of the recommendations from the independent review. The governance to support the delivery of the recommendations was found to be robust and there was found to be effective monitoring in place to assure the onward delivery of each of the recommendations.

The provision of senior leadership and executive-level oversight for the whole of the local LeDeR programme has proven to be of significant benefit, with the positive impact of this being reported by all stakeholders.

The quality checks and the findings from these quality checks, provided some extremely valuable insight concerning several important issues. However, a number of these are not unique to the BNSSG ICB system but do serve as important matters for the local system to address.

It is accepted that upon completion of the review, BNSSG ICB working with local system partners and relevant external stakeholders will retain responsibility for the application of learning arising from this review, along with the ongoing governance for the strategic delivery of the local learning disability and autism programme.

Appendix 1 - Independent Review into Thomas Oliver McGowan's LeDeR Process: phase two

https://www.england.nhs.uk/wp-content/uploads/2020/10/Independent-Review-into-Thomas-Oliver-McGowans-LeDeR-Process-phase-two-_20-October-2020.pdf

Appendix 2 - Assurance Review of the implementation of recommendations following the independent review of the LeDeR process for Oliver Thomas McGowan. March 2023

Recommendations:	The ICB Board receives this update and supports the recommendations to: • Accept the Independent Assurance Report Findings

	• Any ongoing system development through the Learning Disability Health Provider Network reporting to the Mental Health, Learning Disability and Autism Health and Care Improvement Group • Ongoing oversight of LeDeR Governance through BNSSG Outcomes, Quality and Performance Committee.
Previously Considered By and feedback:	Considered at BNSSG ICB Outcomes, Quality and Performance Committee and in individual provider discussions. Key feedback was to welcome the significant activity to date and especially the work undertaken in partnership between NBT and Sirona Care and Health along with the extensive range of co-production work to address health inequalities.
Management of Declared Interest:	None declared
Risk and Assurance:	Without organisational/system sign up there is a risk that the system action will not be delivered This will affect the ability of the wider system across BNSSG to take and embed learning from this. Funding of a consistent model for the Community Learning Disability Nursing team in-reach to both NBT and UHBW
Financial / Resource Implications:	None referenced
Legal, Policy and Regulatory Requirements:	None referenced
How does this reduce Health Inequalities:	LeDeR programme focus is on improving equality and diversity outcomes for people with learning disabilities and autistic people
How does this impact on Equality & diversity	As above
Patient and Public Involvement:	Narrative included in body of report
Communications and Engagement:	To be manged by Comms team in agreement with Executives
Author(s):	Rosi Shepherd Chief Nursing Office and Lesley Le-Pine - Associate LD Projects
Sponsoring Director / Clinical Lead	Rosi Shepherd, Chief Nursing Officer

David Harling
National Deputy Director for
Learning Disability Nursing
Skipton House
80 London Road
London
SE1 6LH

Tuesday 2nd May 2023

Independent Assurance Review

Dear Rosi and Jill, further to completion of the above assurance report and the subsequent peer review, I shared the draft report with Tom Cahill and Nicola Easey for their consideration and feedback.

You will recall that the within the national programme, the internal sign-off for the report was originally agreed by Claire Murdoch, with an explicit understanding that any further actions arising from this work would be the responsibility for the local system to enact; with of course, relevant oversight and support from the regional NHSE team.

Following feedback from Tom and Nicola I can confirm they are both satisfied with the content and findings of the report and have agreed to the report being formally signed off for release.

By way of closure to the process and ahead of a final meeting with Mr and Mrs McGowan, I understand Tom is scheduled to catch up with you Jill in order to assure himself of the relevant governance for any continued strategic work arising from the review. As agreed, I will meet with you both to discuss the finer detail of the report.

Finally, I want to offer a sincere thank you to you both for your support and patience throughout the review, along with the input of all those colleagues who gave their time to be involved in the review.

I am attaching the final version of the report and I very much look forward to meeting with you both.

Yours Sincerely

David Harling
National Deputy Director for Learning Disability Nursing
National Nursing Directorate of the Chief Nursing Officer for England
NHS England

NHS England

CONFIDENTIAL

Assurance Review of the implementation of recommendations following the independent review of the LeDeR process for Oliver Thomas McGowan

March 2023

Background Context

In October 2020 NHS England and Improvement published a phase two independent review into Thomas Oliver McGowan's LeDeR (Learning from Lives and Deaths) Process. The basis of the review was to identify where specific improvements could be made in the quality assurance processes pertaining to the LeDeR process.

The phase two review made a total of 21 recommendations, each relating to specific areas of learning, the independent review panel also suggested several improvements that could be made.

Of the 21 recommendations, 11 of these were intended for enactment by the then Bristol, North Somerset, and South Gloucester Clinical Commissioning Group (BNSSG CCG), now known as Bristol, North Somerset and South Gloucester Integrated Care Board (BNSSG ICB) see appendix 1. The remainder of the recommendations were the responsibility of the Department of Health and Social Care, NHS England & Improvement, and the national LeDeR programme team.

To assure delivery of the local recommendations, the national LeDeR programme team, alongside colleagues from NHS England and Improvement regional team, worked closely with Mr and Mrs McGowan (Oliver's parents) to monitor the progress of these.

In May 2021, Mr and Mrs McGowan met with Claire Murdoch, National Director of Mental Health NHS England, and Rachel Snow-Miller, Head of the LeDeR programme, NHS England (NHSE). During these discussions, concerns were raised about the perceived lack of progress on the recommendations allocated to BNSSG ICB.

NHS England agreed that additional oversight was needed, this would be done with a further assurance review that would identify actions taken, progress made and/or current challenges slowing progress against the previous recommendations allocated to BNSSG ICB. Mr and Mrs McGowan requested that the review would collate evidence of the work currently being delivered locally to address the themes arising from the previous reviews.

The scope of the review would address the above points and would be led by David Harling, Deputy Director for Learning Disability Nursing, NHS England. In formalising the review, an agreed governance document was prepared between parties (see appendix 2).

The aim was to account for what has been achieved since the publication of the independent review, and where relevant, to identify any areas for improvement or where progress has been moderate.

Rationale for Review

The assurance review was designed in partnership with Mr and Mrs McGowan and included an established quality assurance methodology to provide an evidenced-based structure to the process. The review was separated into two stages. The second stage would focus on how improvements are being delivered in practice, using a quality-checking methodology, these being carried out in the form of two independent face-to-face quality checks. This would engage people with lived experience to check the progress of the recommendations in practice and for the review lead to observe directly how the local system was working to improve the lives of people with learning disabilities and autistic people.

The review design was finalised in October 2021 and would use the Structure, Process, and Outcome model (Donabedian,1980 - see page 13). This approach would support gathering all of the relevant information and use the model as an assistive framework for the presentation and analysis of evidence. This would prevent the review process from re-examining legacy information and risk repeating the findings of previous reviews.

The primary focus (stage one) has been to identify what progress has been made against the 11 recommendations. The second stage of the review will use evidence supplied in previous reviews and compare this to what progress looks and feels like in practice. Stage two of this review will include a second approach alongside the above quality checkers previously described and will take the form of two focus groups that will use discussion points taken from the 11 recommendations previously described.

This design for the focus group approach will include both discursive and exploratory elements to help provide intelligence on how the improvements have been made and are working in practice. The outline themes for each focus group are included in appendix 3.

The quality-checking approach will be used to review a sample of services at Southmead Hospital. The intention of using quality checks will be to gain intelligence on how the 11 recommendations are being delivered in practice.

The quality checking process is not exhaustive, instead intended to provide a helpful overview as to how services are being delivered at that time. Once the second stage is completed, the review will formally conclude.

The first quality check will be led by a team of quality checkers made up of people with a learning disability and the other quality check by a team of autistic people. The quality checks will be carried out within the emergency department/and other areas at Southmead Hospital and will include six themes contained in the 11 recommendations set out in the action plan from the independent review. In summary, these are as follows:

- Training Transition Development
- Interventions
- Hospital passport
- Multi-disciplinary team
- Reasonable adjustments

Note: The Quality Checks employ an open and transparent approach, thereby enabling those carrying out the checks, to use their own experiences to assess the quality of care, and in doing so, provide a view that can be often missing from other forms of review. The Quality Checks are founded on the principles of developing an effective partnership with those services and personnel subject to the check, local stakeholders must be engaged as equal partners in the process. The intention is, that any improvements identified as part of the quality check will be the responsibility of the local system to enact.

To facilitate the second stage of the review BNSSG ICB has worked with the NHSE team leading the review to organise these directly with local quality-checking organisations. Once complete, the findings from the

quality checks will be given over to the named executive leads within BNSSG ICB responsible for the LeDeR programme and additionally presented formally during the quality review visit.

Structure Process and Outcomes

The following section summaries for each of the 11 recommendations the conclusion identified from the stage one Structure-Process-Outcome tool. The detailed evidence for this is contained in appendix 4.

Recomendation 3 All those who are new to the role of lead reviewer, or local area contact (LAC), must be allocated a 'buddy' who is experienced in the LeDeR process

Conclusion: The review identified that the 'buddy' system had been established and was working effectively across the system.

Recommendation 5 Dedicated time and administrative support must be given to reviewers and LACs to undertake complex LeDeRs

Conclusion: The review identified that a dedicated and robust arrangement to afford reviewers time and administration support had been established. The administration support was accessible and the documentation reviewed readily accounted both the value and the impact of this resource to reviewers in their completion of LeDeR work.

Recommendation 6 There must be a transparent process for LeDeR in each locality, with robust governance and appropriate resources to ensure that each review is properly monitored in terms of procedure and outcomes

Conclusion: The review is satisfied that both the operational processes, the input of relevant personnel and application of learning from LeDeR are supported by robust governance arrangements.

Recommendation 9 The LAC and the lead reviewer should confirm at the onset of the LeDeR process how much support is needed and what it should look like. Guidance for reviewers should emphasise that when undertaking a LeDeR, there is an onus on a team responsibility to complete the process to the required standards, rather than it falling to an individual (the lead reviewer, in this case).

Conclusion: The review is satisfied that this recommendation is being amply delivered and is subject to ongoing regular review and feedback form those involved.

Recommendation 10 Each CCG must identify an executive lead to be responsible for the LeDeR programme and for ensuring that the board has full sight of progress.

Conclusion: The review is satisfied that this recommendation is being met.

Recommendation 12 The CCG executive lead for LeDeR will ensure that LeDeRs are completed in a timely and correct manner and will intervene where problems are escalated, such as the inability to obtain critical information from the relevant agencies.

Conclusion: The review finds that this recommendation is being effectively delivered in practice across the local system. Where obstacles or new challenges occur, there appears to be sufficient mechanisms in place in ensure timely and coordinated means for resolving such matters.

Recommendation 13 When a multi-agency review (MAR) is indicated, it is important that the correct process and outcomes are achieved. It is therefore expected that where the reviewer and the LAC have no previous experience of a MAR, they will seek support from a 'buddy' who does.

Conclusion: Whilst changes in LeDeR process and the MARs have ensued since the advent of the review, evidence of locally available and timely access to relevant support and/or mediation is in place.

Recommendation 15 In regard to the MAR meeting itself, it is recommended that there is action taken to; ensure that families are central to the process, are offered full sight of all documents, and are invited to attend all or part of the meeting as they wish.

Conclusion: Whilst changes in LeDeR process and the MARs have ensued since the advent of the review, evidence to illustrate delivery of this recommendation was noted and deemed acceptable. The review team observed directly how coproduction had been embraced and had formed a critical element in LeDeR processes locally.

Recommendation 18 There should be an assurance process with regard to providing regular, appropriately documented supervision for individual LeDeR reviewers.

Conclusion: the review finds this recommendation to have been adequately implemented, with clear and appropriate lines of communication in place, in addition to provision of suitable internal processes to safeguard this process.

Recommendation 20 Appropriate support should be available to reviewers, along with strong governance, to ensure that all LeDeR recommendations are robust and actioned in a timely manner, and that lessons learnt are shared nationally.

Conclusion: the review team conclude this recommendation to have been comprehensibly implemented/delivered.

Recommendation 21 Each CCG must formally undertake, document and review its own systems and processes against the learnings and recommendations arising from Oliver's re-review

Conclusion: the review concludes that the necessary structures and processes are in place and fulfilment of this recommendation has been achieved.

Stage One findings

Stage one of the review assured that an array of strategic and operational work was underway or had been embedded in practice assuring the deliverable required by the national LeDeR process, as well as explaining how the learning generated in response to previous points of failures identified within the local system were/had been acted upon.

Since the publication of the recommendations and subsequent scrutiny of evidence as part of this review, some of the national LeDeR system processes have changed. This change was accounted for in this review with an understating that it would have been relevant at the time, but with an awareness further changes had taken place in local delivery. During focus group discussions as part of the review visit, colleagues conveyed their knowledge of the current LeDeR processes and shared differing viewpoints as to the value of these changes.

The findings of stage one of the review confirmed that the overarching governance for LeDeR and its delivery within the BNSSG ICB area has met each of the recommendations. By examining the specific recommendations related to local LeDeR reviews, support to reviewers, engagement of families and people with lived experience, provision of buddying and supervision, and the critical leadership and administrative support necessary to maintain this, the review team was assured that these are in place and supported by appropriate structures along with the necessary resources to ensure sustainability.

The evidence reviewed related to executive accountability and oversight for LeDeR delivery across the BNSSG ICB indicated that the executive Director of Nursing (DoN) for the ICB is held responsible for this. Additionally, minutes, dated correspondence and the local action plans detailed the active input of the DoN in fulfilment of this duty

With regards to the monitoring of and adherence to timescales, including how the system responds to any exceptions, there was sufficient evidence to confirm the effectiveness of this within BNSSG ICB, alongside written provisions within governance documents to highlight shared accountability with other local system partners.

Whilst there is substantial evidence contained within the process section for each recommendation, it is important to note that in reviewing how LeDeR is working in practice, the review determined that there was a clear sense that LeDeR reviewers in particular, were afforded appropriate time, peer support, early mentoring, and

administrative support in order not only to undertake reviews but to ensure each completed review was of high quality.

Following the publication of the original recommendations from the independent review for Oliver, BNSSG ICB commenced the necessary planning to enact these recommendations. However, engagement with Mr and Mrs McGowan both from a local system standpoint, alongside that of the national and regional LeDeR programme should have been more robust. This would have served Mr and Mrs McGowan with a degree of reassurance that upon receipt of the recommendations, the system as a whole was actively responding to these. Had Mr and Mrs McGowan been meaningfully engaged following the publication of the independent review, it is the reviewing team's opinion that this would have helped them understand the rate at which the work was progressing to address the recommendations.

The review of the implementation of the recommendations as a desktop exercise, in addition to the stage two quality review (described below) of how these recommendations, are working in practice (as determined by local system colleagues) has proven extremely valuable. Ensuring Mr and Mrs McGowan's engagement throughout this process has enabled the review methodology to remain relevant, thorough, and credible. This was helpfully assisted by the transparency and candour from the BNNSSG ICB in responding to any requests made by the review team be this individually or on behalf of Mr and Mrs McGowan.

As accounted in the evidence supplied and scrutinised as part of the review, the review team concluded that the overarching governance, delivery, and conformity to the recommendations are appropriate, thorough, and accountable. Following this review, the continued accountability for all future LeDeR programme work will be the responsibility of the ICB and relevant partners.

Stage Two Part A - Quality Review (Focus groups)

The quality review visit was carried out over two days in November 2022, the visit was agreed upon in advance between the NHSE lead reviewer and colleagues from BNSSG ICB. Timetables for these two days are included in appendix 5.

On the first day of the review, NHSE Nursing Directorate Learning Disability Team met with members of the BNSSG ICB and affiliated partners, as part of two focus group sessions. The purpose of the focus groups was to gain a first-hand view of local developments and any barriers to these in their operational and strategic response to the recommendations of the independent review into the death of Oliver McGowan.

Discussions were formed around pre-determined themes which were designed to elicit an open and honest dialogue with participants. The themes for the focus groups were agreed upon in advance with Mr and Mrs McGowan.

A record of all points collected during the focus groups has been drawn from the combined notes of the review team and provides an overview of the discussion(s) that took place see appendix 6. The intention was to explore how written evidence supplied as part of the review aligned people's experiences in practice.

The focus groups elicited a wealth of viewpoints, giving context and meaning to the overarching review, both evidentially in support of progress, it also helped understand some of the philosophical perspectives of local leaders, clinicians and managers.

The review of focus group content accounts the range of quality improvement work underway to improve local services. The narrative heard during the focus groups described a high degree of effort and commitment which was being deployed in the design and implementation of local policy and strategy.

There was a consistent correlation in the detail given throughout this stage from participants to assure the reviewing team of the findings from stage one, also providing further assurance this was being enacted by colleagues in their day-to-day practice. Both focus groups shared a range of opinions concerning the themes being explored, it was evident that working relationships between different services/personnel were mainly positive and inclusive.

The focus group sessions determined that whilst an array of improvements had been achieved, there is still work to be done to continue developing and refining local services so that they continue to be of benefit to people and families. As is the case nationally, there was a unanimous acknowledgement that the sustainability of this remains challenging.

Stage Two-part B – Quality Checkers (Southmead Hospital)

In August and September 2022, two separate quality checks were carried out within the Emergency Department at Southmead hospital. These checks were carried out by recognised quality-checking organisations; namely, the Brandon Trust and Bristol Autism Service.

The review team in partnership with Mr and Mrs McGowan felt this to be an important part of the review, not least because Southmead hospital is where Oliver sadly passed away.

The recommendations from each of these reviews are detailed below and provide a valuable context for understanding not only what has been achieved, but importantly where there are areas of continued challenge or where opportunities exist to further strengthen a given area of improvement.

The Bristol Autism Spectrum Service (BASS) provides support, advice and training across the Bath and Northeast Somerset, Bristol, North Somerset and South Gloucestershire localities. As part of the review, six members from BASS carried out quality checking work within the Emergency department (ED) at Southmead hospital, the work they carried out was supported by an ED audit tool they had developed. Additionally, the BASS team also interviewed members of the psychiatric admissions team to gain a more in-depth understanding of the knowledge and the functions of how this team, work in practice.

The feedback from both of the quality checks was provided by way of a formal presentation to the review team and this also included various members of staff representing the ED, the hospital liaison team, the quality improvement department, the trust board, local commissioners, and managers.

For the most part, both of the quality checks returned a mixture of findings, and it was evident from both feedback and questioning of the reviewers that these checks had been conducted with rigour and are broadly aligned to the themes contained in the recommendations of the action plan from the independent review.

BASS quality check

The BASS quality check feedback can be found in appendix 7 and covers a range of themes/points, along with some direct quotes from members of the quality checking team. The recommendations from the visit were as follows:

- Explore the development of a 'presenting problem' form.
- Adopt the NHS autism wallet card across the service.
- Recruit autistic volunteers to serve as 'Move Makers'
- Promote the use of autism passport & flag on patient records
- Develop some stickers for plugs to charge tablets/phones
- Provide pagers for people who are guided to quiet rooms to prevent them being missed.
- Provide spare phone charger/multi adapters on loan.
- Develop a type of "Keeping me safe in the moment" checklist
- Invite people with lived experience to speak at team meetings
- Invite autistic people to review existing leaflets/information sheets.

Brandon Trust quality check

The Brandon Trust quality check aimed to explore several themes within the hospital to learn how a person with a learning disability or autism would experience the physical environment, how their needs and choices are responded to, and the quality of healthcare they could expect. The feedback can be found in appendix 8 and covers a range of these themes/points, along with some direct quotes from members of the quality-checking team. The recommendations from the visit were as follows:

- The hospital Learning Disability Team may benefit from wearing uniforms that identify them as nurses. (n.b. the review team note the liaison team currently wear a dedicated yellow uniform, which it may be argued makes them easier to identify)
- A review of disabled parking arrangements would help to make sure there is enough provision.
- Accessible maps, using symbols may benefit people with limited literacy
- Installing lower desks or monitors to alert the receptionist of the person's presence.
- Where electronic appointment boards are used, it is important that people with learning disabilities or autism are asked if they need to be called instead.
- Create more quiet areas for people to retreat to if needed, and where possible, more accessible outdoor space.
- Ensure adjustable, softer lighting is provided for people in private rooms.
- Some departments are better at contacting the Learning Disability Nursing Team than others. Implementing a more reliable system and training staff in all departments would ensure a more consistent approach.
- Learning disability and autism training has not been received by all hospital staff and had been stopped during the pandemic. This should start again as soon as possible and will eventually be the Oliver McGowan mandatory training, which will reach all staff and volunteers.
- Training would be further be enhanced by ensuring the co-production of training materials and co-delivery with people who have lived experience.
- Ensure that nurses and consultants are reminded and trained around the issue of 'masking' by an individual with a learning disability or autism.

- A more robust system for using hospital passports is recommended and this is needed nationally.
- More patient information should be made accessible, which would benefit people with learning disabilities and other groups.
- Referring consultants/doctors must be trained on the importance of flagging additional needs and reasonable adjustments on patient's records to ensure joined-up working.
- There should be a more robust electronic system in place that identifies when a person with a learning disability or autism is coming into hospital.

Assurance review conclusions

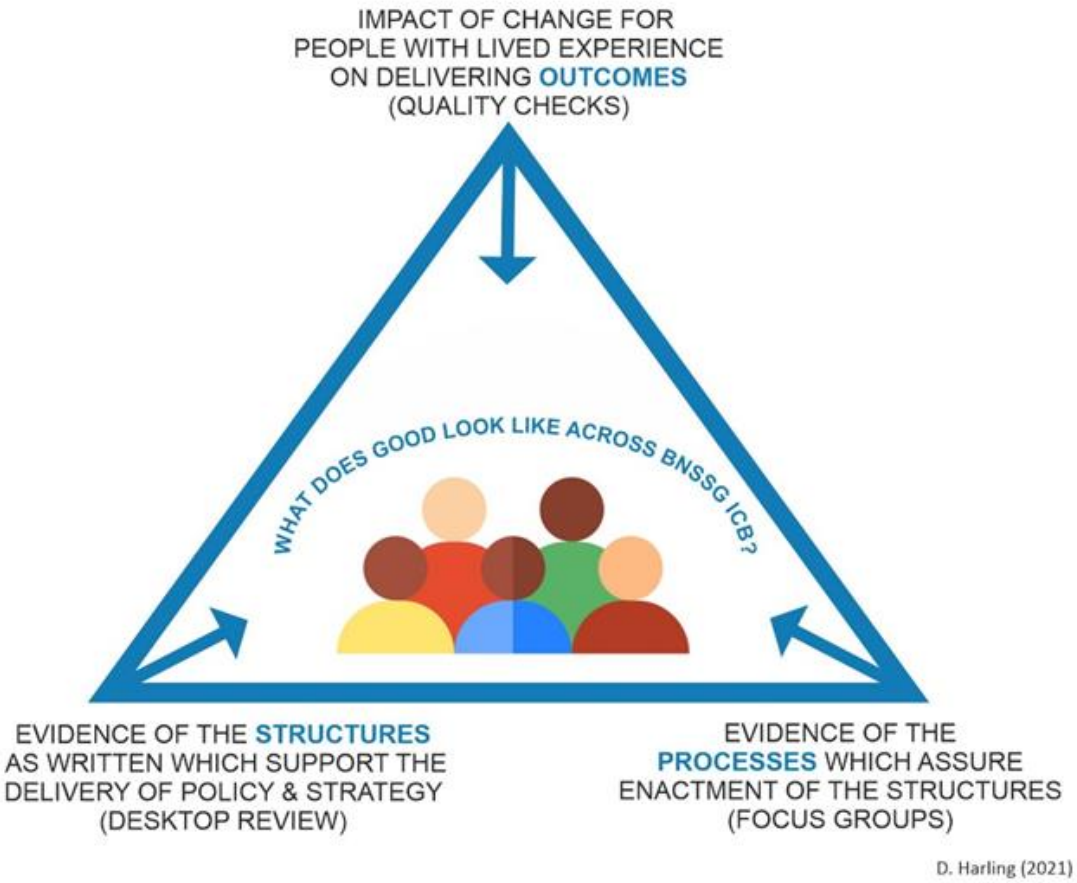
The scope and depth of the review enabled the review team to assess and scrutinize an array of written evidence which supports the delivery of local policy, system processes and strategy. In addition, a range of improvement work and the rationale underpinning these initiatives were also examined in detail.

A critical question for the review team was how to discern from the range and the quality of evidence in written form, what elements had been initiated since the publication of the independent review and whether progress had been made. Through the use of triangulation from the three approaches detailed

above the team was able to gain a good understanding and assurance of the effectiveness and timeliness of the recommendations that have been implemented across the system. Undertaking both focus groups and reviewing quality checkers' findings gave a first-hand narrative of how policy is being implemented, the introduction of new initiatives appears to be having an impact on people working in and using local services; and by which the efficacy of system structures could then be measured.

The use of the Structure-Process-Outcome model (Donabedian 2005) provided the evidence-based framework through which the review could support the collation of evidence relating to local improvements and service delivery, along with first-person accounts heard in the feedback from both the personnel working within services (focus groups), along with those people who access services (quality checks).

The following illustration sets out the methodology for the review.



The application of the above methodology assisted to ensure a comprehensive review of all evidence presented, and its application to a recognised model for evaluating quality and the impact of change. Further details on the Donabedian model for quality-of-care methodology can be found here:

https://www.england.nhs.uk/wp-content/uploads/2022/02/qsir-measuring-quality-care.pdf

In conclusion, from the culmination of the findings for both stage one and stage two (parts A and B) from this review, it is evident that BNSSG ICB has actively implemented all of the recommendations from the independent review. The governance to support the delivery of the recommendations was found to be robust and there was found to be effective monitoring in place to assure the onward delivery of each of the recommendations.

The provision of senior leadership and executive-level oversight for the whole of the local LeDeR programme has proven to be of significant benefit, with the positive impact of this being reported by all stakeholders.

The quality checks and the findings from these, provide some extremely valuable insight concerning several important issues. However, a number of these are not unique to the BNSSG ICB system, but do serve as important matters for the local system to address.

It is accepted that upon completion of the review, BNSSG ICB working with local system partners and relevant external stakeholders will retain responsibility for the application of learning arising from this review, along with the ongoing governance for the strategic delivery of the local learning disability and autism programme.

APPENDICES

Appendix 1

REC No	LeDeR Phase 2 Recommendations	Action
3	All those who are new to the role of lead reviewer, or local area contact (LAC), must be allocated a 'buddy' who is experienced in the LeDeR process.	CCGs
5	Dedicated time and administrative support must be given to reviewers and LACs to undertake complex LeDeRs.	CCGs
6	There must be a transparent process for LeDeR in each locality, with robust governance and appropriate resources to ensure that each review is properly monitored in terms of procedure and outcomes.	CCGs
9	The LAC and the lead reviewer should confirm at the onset of the LeDeR process how much support is needed and what it should look like. Guidance for reviewers should emphasise that when undertaking a LeDeR, there is an onus on a team responsibility to complete the process to the required standards, rather than it falling to an individual (the lead reviewer, in this case).	LACs and lead reviewers
10	Each CCG must identify an executive lead to be responsible for the LeDeR programme and for ensuring that the board has full sight of progress.	CCGs
12	The CCG executive lead for LeDeR will ensure that LeDeRs are completed in a timely and correct manner and will intervene where problems are escalated, such as the inability to obtain critical information from the relevant agencies.	CCGs
13	When a multi-agency review (MAR) is indicated, it is important that the correct process and outcomes are achieved. It is therefore expected that where the reviewer and the LAC have no previous experience of a MAR, they will seek support from a 'buddy' who does.	LeDeR reviewers and LACs

15	In regard to the MAR meeting itself, it is recommended that there is action taken to: • ensure that families are central to the process, are offered full sight of all documents, and are invited to attend all or part of the meeting as they wish	CCGs
18	There should be an assurance process with regard to providing regular, appropriately documented supervision for individual LeDeR reviewers.	CCGs
20	Appropriate support should be available to reviewers, along with strong governance, to ensure that all LeDeR recommendations are robust and actioned in a timely manner, and that lessons learnt are shared nationally.	CCGs
21	Each CCG must formally undertake and document and review its own systems and processes against the learnings and recommendations arising from Oliver's re-review.	CCGs and ICSs

Recommendations from the Independent Review

Appendix 2

Agreed Governance document

Dated: September 2021

O.M Assurance Review

Overview of key stages and agreed governance

Named Personnel for the review

The governance for the assurance review is overseen by BNSSG ICB, with Rosi Sheperd, Executive Director of Nursing (BNSSG ICB) serving as the named accountable officer for the review. BNSSG ICB will be responsible for accepting and delivering the recommendations.

The facilitation and completion of the review is the responsibility of the national nursing directorate, with David Harling, Deputy Director for Learning Disability Nursing, serving as the lead facilitator responsible for delivering the review.

The oversight, support and monitoring for the review and enactment of its recommendations is held by NHS England regional team, (Nursing) with Jill Crook, Director of Clinical Development and Engagement providing the necessary linkage between the named parties.

The findings and any subsequent actions from the review, will be shared with Ruth May, Chief Nursing Officer for England, Claire Murdoch, National Director for Mental Health and Tom Cahill, National Director for Learning Disability and Autism.

NHS England and Improvement National Learning Disability Programme are recipients of any learning being generated by the review, which may serve to assist in the development of policy and practice guidance.

Chronology of rationale and key stages

1. In May 2021 Mr and Mrs McGowan contacted both Ruth May and Claire Murdoch, seeking assurance that the 11 recommendations, taken from Oliver's independent review, which, for the purposes of enactment, were the responsibility of BNSSG ICB and local system delivery partners.

In addition, they requested that the review identify how the 6 areas accounted within the action plan from the independent review, were being addressed in practice. These are as follows:

- **Training**
- **Transition Development**
- **Interventions**
- **Hospital passport**
- **Multi-disciplinary team**
- **Reasonable adjustments**

2. In seeking a degree of independence Mr and Mrs McGowan requested that David Harling lead the review, seeking the permission of both Claire Murdoch and Ruth May. This was agreed in June 2021.

3. The aim of the review was to examine what progress BNSSG ICB had been made in their delivery of the recommendations. By determining this, the review would provide assurance to Mr and Mrs McGowan, BNSSG ICB, and the regional NHSE leads of all progress to date; as well as identifying any areas of continued development/non-conformity.

4. In agreeing to undertake and design the review, David Harling was afforded due autonomy to lead the work. As a result, he worked directly with Mr and Mrs McGowan and BNSSG ICB to agree the format and methodology to be used. The final format was agreed by all parties in October 2021.

5. Following this, all parties agreed that the review format would take the form of two stages. The first stage being, to undertake a thorough review of all correspondence, given over as evidence, to illustrate delivery of each of the 11 recommendations.

This entailed BNSSG ICB supplying David with a wealth of documentation for review. Essentially, the first stage of the review has serviced a quantitative method, by collecting, reviewing, and scrutinizing the data/written evidence.

The progress reports throughout the review will be led by David Harling and shared with Mr and Mrs Mcgowan, BNSSG ICB, NHS England and Improvement Regional Team (Nursing) and the NHS England and Improvement National Learning Disability programme.

Upon completion of the review, a copy of the final review report will be shared with the Claire Murdoch, Tom Cahill and Ruth May.

The second stage of the review then applies a qualitative approach, by seeking to understand the impact of the recommendations from a practice perspective. In consultation with Mr and Mrs McGowan, and BNSSG ICB, it was agreed (September 2021) that this would take the form of the following two approaches:

i) **Focus group method** – meeting with a sample of personnel.

ii) **Quality check method** – focused on a clinical area e.g

Southmead ED.

The focus group method would recruit first-hand, narratives from a sample of personnel, for whom the 11 recommendations have a direct bearing on their day-to-day work. This would allow for a discursive and exploratory approach to understanding individuals' views of how the improvements are working in practice.

The quality check method would engage the approved NHS England quality checking methodology by commissioning an organisation (or people with lived experience who are familiar with leading a quality check), to utilise one of the nationally approved toolkits to review a given area of service.

The quality checking method is an open and engaging means of working in collaboration, to assess the quality of a service. In this instance, the check would incorporate and make due consideration of the 6 areas from the action plan, as detailed above.

In delivering the quality check, Claire Murdoch gave written assurance to David Harling that in the course of the review, that should it be required, he could utilise the expert advisors employed within the national learning disability programme to engage in this part of the review.

Alternatively, one of the nationally approved independent quality checking organisations could be commissioned to deliver this.

In learning about quality checks, Mr and Mrs McGowan requested that the emergency department at Southmead hospital be prioritised for a quality check, and for which there is a dedicated quality checking toolkit for emergency departments.

The relevance of quality checking the Emergency Department is due to the fact that each of the 6 themes identified in the independent review, have some relationship to this department, and the way in which it operates with the wider hospital, and also community learning disability services.

6. Once this second, final stage is complete, the assurance review report will be finalised to include a conclusion, along with any recommendations. Once accepted by BNSSG ICB, a copy of the report will be provided to all named personnel (as detailed above).

As determined at the outset, from a governance standpoint the review reports to BNSSG ICB executive, with the responsibility for any subsequent actions, being addressed by the local system. Oversight and support will continue from NHS England and Improvement Regional team (nursing) colleagues.

This arrangement complements current established processes at the local level and supports the existing interface between NHSE regional team and BNSSG ICB and partners.

7. Upon completion of the review, it is formally acknowledged that all subsequent governance, including additional queries will be managed by BNSSG ICB.

8. It is accepted that the review will conclude no later than the end of November 2022.

Appendix 3

Focus Group themes

FOCUS GROUP 1: LeDeR developments & Improvement

in practice

Themes to explore:

1. Support for reviewers.
2. 'Buddying' system.
3. Value of LeDeR.
4. Healthcare for all vs. inequalities
5. Assuring longevity/lessons learnt.
6. Oliver McGowan Mandatory Training

Focus Group 2 themes

FOCUS GROUP 2: Exploring system working between partners

Themes to explore:

1) Why are we not getting it right for people with learning disabilities and autistic people?

2) Can you tell me what good transition looks like locally and also what you consider to be the biggest challenges?

3) What are you doing locally to better understand and address the systemic factors?

4) Hospital passports - safeguarding any future recurrence of failings

5) 'Reasonable adjustments'. Barriers/solutions?

Appendix 4 Structure Process Outcome LeDeR data

REC No	**Recommendation:** All those who are new to the role of lead reviewer, or local area contact (LAC), must be allocated a 'buddy' who is experienced in the LeDeR process.		
	STRUCTURE	**PROCESS**	**OUTCOME**
3	The below statements of conformity are taken from BNSSG Compliance Matrix ***All LeDeR reviewers in BNSSG CCG are 'buddied' with a more experienced reviewer. This has been in place since March 2020.***	BNSSG has supplied evidence in testimony of the work to date to support the statements of conformity accounted within the BNSSG compliance matrix and the associated documentary evidence supplied as part of this oversight review. **Provision of a new 'LeDeR Reviewer: Welcome & Information pack' which accounts the following processes:** • **Context for review** • **Provision of a buddy** • **Access to Peer Support Meetings** • **Provision of dedicated LeDeR administration** **when organising/undertaking reviews.** • **Access to the Local Area Coordinator (LAC).** • **Development of a Clinical Case Review Panel**	This includes themes/evidence identified which supports improved outcomes: Each of these will be explored as part of phase 2 **The evidence reviewed clearly identifies a growth in the number of LeDeR reviewers.** **The scope of actual project work arising from the learning form LeDeR reviews appears significant.** **From the information provided it appears that BNSGCCG now have the highest number of LeDeR reviewers in the Southwest.** **The evidence supplied and datemarks of the documentation supplied, illustrates that work to address the**

		• **Function and access to the Multi agency review (MAR).** • **Additional administrative support processes are detailed.** ***A sample of email correspondence between new reviewers and LeDeR administration has also been supplied/reviewed.** ***LeDeR reviewer forms/recruitment and also LeDeR administration job profiles have also been supplied/reviewed.** .	**recommendations of the independent review, commenced around March 2020.** **From what is described by way of learning and projects, it appears the majority of these are coproduced. Additionally, from direct accounts from those involved in LeDeR it is evident that dedicated support, time, preparation and debrief was now in place.** **CONCLUDING POINT: The review identified that the 'buddy' system had been established and was working effectively across the system.**

REC No	**Recommendation:** Dedicated time and administrative support must be given to reviewers and LACs to undertake complex LeDeRs.		
	STRUCTURE	**PROCESS**	**OUTCOME**
5	The below statements of conformity are taken from BNSSG Compliance Matrix ***BNSSG employs a LeDeR administrator to support all LeDeR reviewers with all notes pulling appointments as required.*** ***Line managers of all LeDeR reviewers are required to sign a release form to confirm that the person has capacity within their workload to undertake the reviews, regardless of complexity.*** ***There is a clear mandate that line managers effectively supervise LeDeR reviewers and flag any issues to the local area coordinator.***	BNSSG has supplied evidence in testimony of the work to date to support the statements of conformity accounted within the BNSSG compliance matrix and the associated documentary evidence supplied as part of this oversight review. **Evidence of the provision of LeDeR administration and the support and coordination this role affords to reviewers has been supplied. This takes the form of a sample of email correspondence between new reviewers and LeDeR administration.** **Additional to the array of email correspondence supplied/reviewed, it is evident from the range and scope of documentation supplied that reviewers are afforded support/advice/and direction where required.** **From information reviewed/supplied it is not possible to determine whether, at an individual reviewer level, they are supported in their respective role/employ to complete the more complex reviews. To a degree, this is something that is out with the control of the CCG.**	This includes themes/evidence identified which supports improved outcomes: <u>Each of these will be explored as part of phase 2</u> **By speaking with a sample of reviewers and in scrutinising a variety of evidence, the review established that this recommendation was being fulfilled in practice.** **The review met with and heard from practitioners involved in undertaking and overseeing LeDeR reviews and processes. The range of testimony provided by those involved provided clear indication that both time and administration arrangements were being afforded those undertaking LeDeR work.**

			CONCLUDING POINT: The review identified that a dedicated and robust arrangements to afford reviewers time and administration support had been established. The administration support was accessible and the documentation reviewed readily accounted both the value and the impact of this resource to reviewers in their completion of LeDeR work.

REC No	**Recommendation:** There must be a transparent process for LeDeR in each locality, with robust governance and appropriate resources to ensure that each review is properly monitored in terms of procedure and outcomes.		
	STRUCTURE	**PROCESS**	**OUTCOME**
6	The below statements of conformity are taken from BNSSG Compliance Matrix ***BNSSG has an established monthly clinical case review panel. The panel has a minimum membership of a GP, nurse social worker, and other health professionals.*** ***Each completed initial review is quality assured by the panel.*** ***LeDeR reviews are governed by the LeDeR steering group which meets monthly. Case review panel minutes are included in steering group papers every month.*** ***LeDeR progress is also reported monthly to the quality committee, Governing body through QPR.***	BNSSG has supplied evidence in testimony of the work to date to support the statements of conformity accounted within the BNSSG compliance matrix and the associated documentary evidence supplied as part of this oversight review. **Evidence of the LeDeR local governance process along with structural diagrams have been supplied providing the necessary detail of established/ongoing processes.** **Detail in the form of a local policy has been supplied to illustrate the accountabilities of the LeDeR steering group with associated terms of reference and outline procedures.** **Minutes of prior steering groups including any necessary mitigations (use of risk log) to agenda items has been supplied for review. Governing body reports have been seen which provide statistical overview, context and mitigations for all work to date.**	This includes themes/evidence identified which supports improved outcomes: <u>Each of these will be explored as part of phase 2</u> **The overarching governance for all LeDeR processes is overseen by the ICB and relevant partners. The examination of all documentation pertaining to governance and the enactment of this in practice illustrated how effective the system was now operating.** **Effective resource allocation, provision of dedicated LeDeR reporting structures, in addition to robust delivery, maintenance and review of governance processes was highly accountable/judicious.** **It was helpful to review a range of initiatives arising from the LeDeR review learning, many of which are focused on specific themed innovations. This includes mention of projects relating to improving**

		Provision of monthly exception reports relating explicitly to the LeDeR work locally has been supplied. These reports follow an accepted format, detailing no of deaths (cumulatively), no of reviews, covid related activity, comparative data by month, account of learning to date, and current assurance processes. **Minutes of the Quality committee have also been supplied for review, these follow an orderly structure accounting update of local LeDeR programme demographic/data, alongside points for action for the committee.** **Evidence of the peer support group process has been supplied, in addition to email communications to attendees ahead of/in follow up, to given meetings.**	**catheter care and also constipation projects.** **The inclusion of people with lived experience in the design and development of local processes to support effective delivery of LeDeR was clearly evident and there is a clear interface between the engagement of staff and people with lived experience within the overarching governance of LeDeR led by the ICB.** **CONCLUSION: The review is satisfied that both the operational processes, the input of relevant personnel and application of learning from LeDeR are supported by robust governance arrangements.**
REC No	**Recommendation:** The LAC and the lead reviewer should confirm at the onset of the LeDeR process how much support is needed and what it should look like. Guidance for reviewers should emphasise that when undertaking a LeDeR, there is an onus on a team responsibility to complete the process to the required standards, rather than it falling to an individual (the lead reviewer, in this case).		
	STRUCTURE	**PROCESS**	**OUTCOME**

9	The below statements of conformity are taken from BNSSG Compliance Matrix ***After completing BNSSG LeDeR training reviewers are sent a welcome pack with comprehensive information.*** ***This includes guidance for reviews, the 'buddying' process, peer support group, and timescales for completion and the case review panel process.*** ***All reviewers are automatically invited to peer support and the case review panel signs off the final review. A review sign off is never left to one individual.***	BNSSG has supplied evidence in testimony of the work to date to support the statements of conformity accounted within the BNSSG compliance matrix and the associated documentary evidence supplied as part of this oversight review. **Evidence of the new 'LeDeR Reviewer: Welcome & Information pack' has been supplied/reviewed and accounts the following processes:** • **Context for review** • **Provision of a buddy** • **Access to Peer Support Meetings** • **Provision of dedicated LeDeR administration** **when organising/undertaking reviews.** • **Access to the Local Area Coordinator (LAC).** • **Development of a Clinical Case Review Panel** • **Function and access to the Multi agency review (MAR).** • **Additional administrative support processes are detailed.**	This includes themes/evidence identified which supports improved outcomes: <u>Each of these will be explored as part of phase 2</u> **The information and 1:1 correspondence reviewed clearly accounted that the Local Area Coordinator adopts an 'open door' policy and makes themself readily available, providing a timely and supportive response, and deploying an effective team approach.** **Focus groups testimony and observation accounted the support and enablement that all those involved in LeDeR locally now feel. The provision of team approach and shared accountability across system partners was credible/evidenced.** **CONCLUSION: The review is satisfied that this recommendation is being amply delivered and is subject to ongoing regular review and feedback form those involved.**

		Evidence of email correspondence between reviewers and LeDeR administration/LAC has also been supplied/reviewed. Provision of a 'team approach' was evident in the communications reviewed. **Evidence of email correspondence relating to support being provided by the LAC to reviewers has been supplied/reviewed. This includes evidence of email communications/deliberations concerning specific cases and review outcomes/recommendations.**	
REC No	**Recommendation:** Each CCG must identify an executive lead to be responsible for the LeDeR programme and for ensuring that the board has full sight of progress.		
	STRUCTURE	**PROCESS**	**OUTCOME**

10	The below statements of conformity are taken from BNSSG Compliance Matrix ***BNSSG appointed the CCG Director of Nursing as the executive lead for the LeDeR program in July 2020.***	BNSSG has supplied evidence in testimony of the work to date to support the statements of conformity accounted within the BNSSG compliance matrix and the associated documentary evidence supplied as part of this oversight review. **Correspondence supplied/reviewed in evidence of wider recommendations. This illustrates the input and the executive oversight of the executive director of nursing.** **Minutes of meetings supplied/reviewed account the attendance of the executive director of nursing and standing membership of this postholder at quality reviews and governing body meetings.** **Evidence in the form of the local policy framework, accounts the executive director of nursing is the responsible and named executive lead and is detailed in a variety of the documentation supplied/reviewed.** **The local LeDeR policy framework details the role and duty of the executive director of nursing and confirms that this postholder is assigned as the executive lead for this work.**	This includes themes/evidence identified which supports improved outcomes: <u>Each of these will be explored as part of phase 2</u> **There is a robust interface led by the executive director of nursing within the ICB, which from the review of minutes the structural design and accountability framework, clearly highlights the active input of this individual as accountable officer.** **The review team note how the executive lead had taken an extremely proactive approach to delivering the remit of the LeDeR programme locally. By observation this individual readily embraced the recommendations and engaged a transformational leadership approach to delivery of these. From review of relevant papers, it was evident that the executive lead had made LeDeR and associated programme a priority and was directly ensuring that the board both assured and were accountable to ensuring delivery of LeDeR in practice.**

		Implementation, governance and local structure charts all explicitly account the input and duty of the executive director of nursing, as the named executive lead. **It should be noted that all direct correspondence and organisation of this review has been arranged with/via the executive director of nursing, thereby evidencing the responsibility of this role in practice.**	**The named executive for leader maintained an effective level of contact and visibility.** **CONCLUSION: The review is satisfied that this recommendation is being met.**
REC No	**Recommendation:** The CCG executive lead for LeDeR will ensure that LeDeRs are completed in a timely and correct manner and will intervene where problems are escalated, such as the inability to obtain critical information from the relevant agencies.		
	STRUCTURE	**PROCESS**	**OUTCOME**

12	The below statements of conformity are taken from BNSSG Compliance Matrix ***LeDeR data on case progress is reported monthly to the LeDeR steering group quality committee and the governing body.*** ***The executive lead intervenes when required, which includes executives from other agencies.***	BNSSG has supplied evidence in testimony of the work to date to support the statements of conformity accounted within the BNSSG compliance matrix and the associated documentary evidence supplied as part of this oversight review. **A sample of email correspondence has been supplied/reviewed which details a range of information accounting local LeDeR data, alongside illustrations of the support structures responsible for overseeing and governing the process.** **Minutes of meetings and email communications have been supplied/reviewed which illustrate the process for actioning and resolving any issues arising from reviews/peer support meetings/LAC feedback and executive meetings.** **There is evidence of the executive director of nursing supporting the LeDeR LAC postholder in order to service regular contact/direct feedback loop to address various matters.** **A sample of minutes/records/data evidence of local tracking, progress, and monitoring of the overall LeDeR programme has been put forward. The data therein and presentation of evidence, accounts a**	This includes themes/evidence identified which supports improved outcomes: <u>Each of these will be explored as part of phase 2</u> **The collective review and compilation of evidence shows that a formal, orderly and comprehensive process is now in place.** **This focus and emphasis on the importance of the LeDeR proves locally conveys confidence to each of the individuals and the team involved and places due priority on the LeDeR programme as a valuable method.** **From interviews/focus group feedback form those engaged in the LedeR process, there was a unanimous acknowledgement that fulfilment of this recommendation was taken extremely seriously.** **CONCLUSION: The review finds that this recommendation is being effectively delivered in practice across the local system. Where obstacles or new**

		timeliness and efficiency in responding to and resolving any queries/matters arising. **The evidence supplied, readily accounts learning points and actions for address across the programme. The provision of BNSSG LeDeR activity tables, illustrates an ongoing overview and scrutiny process for monitoring & understanding the local picture.**	**challenges occur, there appears to be sufficient mechanisms in place in ensure timely and coordinated means for resolving such matters.**
REC No	**Recommendation:** When a multi-agency review (MAR) is indicated, it is important that the correct process and outcomes are achieved. It is therefore expected that where the reviewer and the LAC have no previous experience of a MAR, they will seek support from a 'buddy' who does.		
	STRUCTURE	**PROCESS**	**OUTCOME**

13	The below statements of conformity are taken from BNSSG Compliance Matrix ***BNSSG has a clear MAR a policy which is available on the website and the MAR process is strictly adhered to.*** ***Reviewers always involve buddies where required, and if necessary, there will be co-contributors in the MAR, in order to up-skill and develop the less experienced reviewers. The LAC also meets with the reviewers to provide guidance and supervision.***	BNSSG has supplied evidence in testimony of the work to date to support the statements of conformity accounted within the BNSSG compliance matrix and the associated documentary evidence supplied as part of this oversight review. **A copy of the new 'LeDeR Reviewer: Welcome & Information pack' has been supplied/reviewed, which clearly accounts role/provision/accessing of buddying arrangements for reviewers. The pack covers the following key areas:** • **Context for review** • **Provision of a buddy** • **Access to Peer Support Meetings** • **Provision of dedicated LeDeR administration** **when organising/undertaking reviews.** • **Access to the Local Area Coordinator (LAC).** • **Development of a Clinical Case Review Panel** • **Function and access to the Multi agency review (MAR).** • **Additional administrative support processes are detailed.**	This includes themes/evidence identified which supports improved outcomes: <u>Each of these will be explored as part of phase 2</u> **The evidence reviewed clearly identifies a growth in the number of LeDeR reviewers all of whom are supported via a developed buddying system.** **The scope of work relating to this recommendation appears significant.** **The evidence supplied and datemarks of the documentation supplied, illustrates a 'live' arrangement for provision of buddying support, which is led by the Local Area Coordinator.** **From what is described by way of learning and the structures for reviewing progress, it appears the system set up in relation LeDeR adequately seeks to learn from, adjust, or change based on the feedback it receives.**

		A sample of email correspondence between new reviewers and LeDeR administration has also been supplied/reviewed. **In addition, other email correspondence containing content which supports the real-time provision and functions of the 'buddying' role and embedding of this into local process has been supplied/reviewed.** **Additional evidence of peer support reviews has been supplied, dated accordingly and detailing attendees present.**	**CONCLUSION: Whilst changes in LeDeR process and the MARs have ensued since the advent of the review, evidence of locally available and timely access to relevant support and/or mediation is in place.**
REC No	**Recommendation:** In regard to the MAR meeting itself, it is recommended that there is action taken to: • ensure that families are central to the process, are offered full sight of all documents, and are invited to attend all or part of the meeting as they wish.		
	STRUCTURE	**PROCESS**	**OUTCOME**

15	The below statements of conformity are taken from BNSSG Compliance Matrix ***In BNSSG family members are central to the review process and are the first person the reviewer contacts.*** ***All documents and meetings include the family (if they wish).*** ***In BNSSG the MAR chair is experienced and trained in chairing multi agency meetings and the clinical case review panel includes safeguarding experts who advise the chair of the MAR.***	BNSSG has supplied evidence in testimony of the work to date to support the statements of conformity accounted within the BNSSG compliance matrix and the associated documentary evidence supplied as part of this oversight review. **The provision of minutes the local LeDeR Multi agency review (MAR) meetings demonstrate, via a standing agenda item, that the process appears supportive of placing the learning generated from specific cases, as a core part of the process. This is achieved via a regular presentation in the form of pen pictures of real cases.** **The attendance at the MAR review meetings appears appropriate and representative of relevant stakeholders.** **The local annual LeDeR report accounts the detailed input of families to the MAR process. Describing in 20/21 six MAR's being held with two of these actively involving the input of family members, albeit via online platform (due to covid). Evidence of having reviewed this process is present, alongside the delivery of preparatory sessions for family members of the MAR to ensure preparedness, due sensitivity and offer of support.**	This includes themes/evidence identified which supports improved outcomes: <u>Each of these will be explored as part of phase 2</u> **Evidence reviewed from specific email correspondence accounted how families are readily invited to engage in the MAR and other aspects of the LeDeR process. Aside from the procedural aspects of being engaged/involved, it will be important to collect a level of narrative from these families to determine what it felt like for them, what they valued and where any changes might help.** **The innovative projects developed as part of the learning from LeDeR, appear to be founded in a coproduced approach, involving people with lived experience and family members.** **CONCLUSION: Whilst changes in LeDeR process and the MARs have ensued since the advent of the review, evidence to illustrate delivery of this recommendation was noted and deemed acceptable. The**

		Copies of email correspondence clearly illustrate the active engagement of family members within the MAR process, including options for adjusting their input, alongside sensitive and compassionate use of language and offers of support. Additionally, the provision of support information for those family members engaged in the correspondence is noted. **Evidence was supplied of a 'LeDeR service user forum' which services a number of aims, placing the voice of people with lived experience and their families, as key stakeholders in ensuring the wider system engages and responds to their input/ideas.**	**review team observed directly how coproduction had been embraced and had formed a critical element in LeDeR processes locally.**
REC No	**Recommendation:** There should be an assurance process with regard to providing regular, appropriately documented supervision for individual LeDeR reviewers.		
	STRUCTURE	**PROCESS**	**OUTCOME**

18	The below statements of conformity are taken from BNSSG Compliance Matrix ***BNSSG reviewers have a peer support group and direct access to the LAC for advice and guidance.*** ***Reviewers are employed by different agencies in the system with different line managers.***	BNSSG has supplied evidence in testimony of the work to date to support the statements of conformity accounted within the BNSSG compliance matrix and the associated documentary evidence supplied as part of this oversight review. **Evidence was supplied reviewed which details written communications between LeDeR reviewers and the LAC, in addition to other external parties.** **Email correspondence was supplied and reviewed which illustrates the support role of the LAC, the provision and offer of both direct support and reflective practice to reviewers.** **The local 'LeDeR Reviewer: Welcome & Information pack' accounts the structures for ensuring how reviewers are supported and what they can expect. It sets out the structural support processes and explains how these operate within the overarching review process.** **Email correspondence has been supplied and reviewed which highlights the LeDeR administrator role with reviewers, assistance with requests/queries.**	This includes themes/evidence identified which supports improved outcomes: <u>Each of these will be explored as part of phase 2</u> **The evidence reviewed and accounted as part of the process section, clearly details a range of measures and governance processes in place to assure delivery of the recommendation.** **Dated email correspondence between the LeDeR coordinator and administrative support team noting contacts, supervision session dates, follow up appointments and where required, rescheduling/queries, provided the necessary assurance of fulfilment of this recommendation.** **The review team heard directly from LeDeR reviewers who acknowledged provision of both support, supervision and debrief, alongside buddying and peer support meetings to be in place.**

		Email correspondence has been supplied and reviewed which accounts the active role of the LAC in supporting and facilitating individual LeDeR review processes including advice/support to new reviewers. In addition, email evidence has been supplied and reviewed detailing the response of the LAC to queries or process issues with reviewers, with evidence of such matters having been addressed and resolved.	**CONCLUSION: the review finds this recommendation to have been adequately implemented, with clear and appropriate lines of communication in place, in addition to provision of suitable internal processes to safeguard this process.**
REC No	**Recommendation:** Appropriate support should be available to reviewers, along with strong governance, to ensure that all LeDeR recommendations are robust and actioned in a timely manner, and that lessons learnt are shared nationally.		

	STRUCTURE	PROCESS	OUTCOME
20	The below statements of conformity are taken from BNSSG Compliance Matrix ***BNSSG has a 'buddying' and peer support system in place, as well as regular access to the LAC.*** ***Support structures for reviewers will be strengthened.*** ***LeDeR recommendations are robust and actioned in a timely manner and include system action plans and contracts with providers.*** ***BNSSG is an active participant in the regional LeDeR operational group which also shares lessons/learning from reviews.*** ***All recommendations are included in the annual report which is published and on reported nationally.***	BNSSG has supplied evidence in testimony of the work to date to support the statements of conformity accounted within the BNSSG compliance matrix and the associated documentary evidence supplied as part of this oversight review. **The range of documentation reviewed clearly describes the role/provision/access of buddying arrangements for reviewers. Specifically, the support arrangements and governance to support this is accounted within the welcome pack and is covered in the following key areas:** • **Context for review** • **Provision of a buddy** • **Access to Peer Support Meetings** • **Provision of dedicated LeDeR administration** **when organising/undertaking reviews.** • **Access to the Local Area Coordinator (LAC).** • **Development of a Clinical Case Review Panel** • **Function and access to the Multi agency review (MAR).**	This includes themes/evidence identified which supports improved outcomes: <u>Each of these will be explored as part of phase 2</u> **The evidence reviewed illustrates the provision of real-time 'buddying' support processes and illustrates where/how the buddying function is working in practice.** **An array of evidence was reviewed which accounts how this recommendation is being fulfilled in practice. Focus group discussions with the review team centred around the issue of support and governance at all levels of LeDeR locally. The overall feedback was extremely positive and supportive of the changes which have been made since enactment of the recommendations.** **CONCLUSION: the review team conclude this recommendation to have been comprehensibly implemented/delivered.**

		• **Additional administrative support processes are detailed.** **Of the documentation reviewed, there was clear evidence of both peer support reviews, alongside 1:1 buddying support sessions, as well as support communications between the LAC and the reviewers.** **Minutes contained within email correspondence between new reviewers and LeDeR administration accounts open exchanges concerning support offered and processes to follow.**	

REC No	**Recommendation:** Each CCG must formally undertake, document and review its own systems and processes against the learnings and recommendations arising from Oliver's re-review.		
	STRUCTURE	**PROCESS**	**OUTCOME**
21	The below statements of conformity are taken from BNSSG Compliance Matrix ***BNSSG developed a comprehensive action plan in response to the learning and recommendations outlined in Oliver McGowan independent review.*** ***BNSSG and partners have implemented many of the recommendations and the governance processes for completion of this action plan will be facilitated via the BNSSG LeDeR steering group, the quality committee, and the governing body.***	BNSSG has supplied evidence in testimony of the work to date to support the statements of conformity accounted within the BNSSG compliance matrix and the associated documentary evidence supplied as part of this oversight review. **In consideration of each of the above recommendations and the 'PROCESS' evidence contained therein, it is apparent that a comprehensive system response has been developed as part of both establishing the LeDeR process across BNSSG CCG, and latterly, that the provision of the recommendations from the independent review, have assisted the executive in helping to assure the governance arrangements for this programme of work.** **The evidence reviewed details a 'ward to board' approach, from representation and regularity of various meetings to the mechanism for responding to the learning being generated; including how this is recorded/tracked.** **At an individual level the range of correspondence reviewed clearly accounted an open/accessible**	This includes themes/evidence identified which supports improved outcomes: <u>Each of these will be explored as part of phase 2</u> **In testimony of this recommendation the LeDeR action plan and the governance structures which support this were duly noted and the evidence underpinning this including risk management, progress monitoring and shared decision making provided confirmation of fulfilment of this recommendation.** **The review was able to scrutinize all available evidence and triangulate this with an understanding of as to how this was/is being enacted locally in practice.** **The review team note how all personnel they met, had embraced the learning and indeed the impact of Oliver's story in order to ensure improvements are made.**

		process in place, with the Local Area Coordinator assuming lead facilitation for this and serving a variety of functions to ensure both consistency of approach, as well as ensuring clear accountability for action at all levels.	**The leadership and tenacity of the Learning disability and Autism director (whose role includes LedeR) to ensure Olivers legacy and the learning from the re-review, serves as a critical benchmark for all current and future programmes was exemplary.** **CONCLUSION: the review concludes that the necessary structures and processes are in place and fulfilment of this recommendation has been achieved.**

Appendix 5: Quality Review Agendas

Bristol, North Somerset and South Gloucestershire Integrated Care Board

LeDeR Review visit with NHS England

David Harling

Tuesday 22nd November 2022

Programme for the day

9.30am **Focus Group 1- LeDeR developments & improvements in practice**

Participants - Alison Moon, Rosi Shepherd, Juliane Matthies – GP lead, Lisa Williams – Sth Glos Council, Chris Cox, North Somerset Council, Nicky Powell – NHSE Region, Sam-Fox Keating – Bristol City Council, Lucy Watson, Emily Greentree, Daniella Daniels, Lesley Le-Pine

10.30am **Break**

10.45am **Focus Group 2 - Explore system working between partners**

Invited Participants – Sarah Whitaker - Sirona, Deb Parsons UHBW, Gifty Markey NBT, Mark Goninon UHBW, Jeff Parry - Milestones, Eve Salthouse Brandon, Claire Maine - Milestones. Zoe Gannaway – AWP. Juliane Matthies – Learning Disability GP lead, Alison Moon, Rosi Shepherd, Lesley Le-Pine, Nicky Powell NHSE

12.00am **Lunch – Square Food Foundation**

12.45am **Learning from LeDeR – ICB work programme developments Lesley Le-Pine**

1.45pm Break

2.00pm **Poo Matters – North Somerset People First**

2.30pm How far have we come? Discussion

What's been learned, achieved, and the challenges

Invited Participants – Alison Moon, Rosi Shepherd, Nicky Powell NHSE, Juliane Matthies, Lesley Le-Pine BNSSG ICB, Steve Hams NBT, Sarah Whitaker - Sirona, Deb Parsons UHBW, Gifty Markey NBT, UHBW, Jeff Parry - Milestones, Eve Salthouse Brandon, Claire Maine - Milestones. North Somerset People First, Tracy Pouard - Sirona

3.30pm **Close**

Venue - 360, Marlborough Street, Bristol, BS1 3NX Room – Conference Room 4th Floor

Quality visit agenda day two

Bristol, North Somerset and South Gloucestershire Integrated Care Board

North Bristol NHS Trust

Review visit with NHS England

David Harling

Wednesday 23rd November 2022

Programme for the day – VENUE Southmead Hospital

10.30am **David Harling – guided tour of Southmead Hospital**

1.15pm **ED Autism audit – MS Teams online meeting**

(Seacole Room – THQ)

Audit findings and recommendations

Ben Stunell, Ruth Revell, Ben Argo, Sam Mignano, Chrissy Lawrence, Jake Alberts

Finish – 2.15

2.30 **Brandon Quality Checkers - Feedback Session**

(Cabot Board Room – Brunel Building)

Adventurer's team report and findings of site visits and meetings at Southmead

3.45 BREAK

4.00 **NBT Quality Presentations**

(Cabot Board Room – Brunel Building)

Steve Hams

- Learning and achievements at Southmead Hospital
- Learning Disability and Autism Liaison Team

5.00pm **Close**

Appendix 6

Focus group discussion notes

The following points are drawn from the combined notes of the review team. And provide an overview of the discussion(s) that took place. Points detailed in italics represent direct commentary from participants. Additionally, the intention was to explore how written evidence supplied as part of the review accorded with the enactment and delivery of this in practice.

- LeDeR was an integral focus of the discussion and members of the focus group confirmed that they had in the past two years '*transformed'* their approach to completing these types of reviews. '*The ICB/Local Area have 20+ reviewers who utilise every tool at their disposal'* in order to ensure that reviews are '*always completed in a timely manner'* and to a '*high standard'*. There is also now a '*Review Group*' who meet regularly and review every single case which adds an extra layer of oversight and assurance.

- Colleagues confirmed that administrative support for LeDeR locally is '*exceptional*', '*well organised*' and '*reliable'*. There was a consistent amount of feedback concerning the support those involved in LeDeR receive. '*It's all about coordination and having the right focus and support and we have that'.*

Colleagues talked about buddying describing *the support 'we receive from one another as reviewers is excellent'*, alongside offering consistent mention of '*the real value of having ****** as our main point of contact'.*

- We were told that *'LeDeR is always talked about'* and '*with the development of the LeDeR governance groups, we are always looking at how we can improve our services'. 'Families like Oliver's should be able to expect better and for this to be delivered'.*

- The review team were able to discern that the themes and learning that arise from each LeDeR review directly inform the improvement work of the organisation(s). Examples were

provided including the '*LeDeR user reps'* and '*the development of our various health equalities initiatives, such as Poo Matters'.*

- Locally there had been some innovation in the design of what was described as a '*LeDeR Bible'* which was described as a singular Administration Pack (this was seen in phase 1) containing all relevant LeDeR information that '*could be used by anyone involved in the process to support their understanding of it'.*

- It was also pleasing to hear that work has been undertaken to '*co-produce lots of information with local self-advocacy groups'* and that it was recognised that co-design was an important part of the overall response to improving services for people and families. We were told that, nationally, *'self-advocacy needed to increase the voice of people with a learning disability'* One respondent commented that *'we are getting better at enabling people to be more visible within our local services'.* Additionally, it was said that '*this is something that the ICB are actively seeking to address locally'*.

- However, there was some dissatisfaction expressed at the current format of the new LeDeR reporting systems as it was felt to be more of a '*tick box exercise'* that '*doesn't allow for meaningful recording of information (people's stories) anymore*'. It was also felt to be '*too academic in design and function'*.

- Some members of the group explained that they felt the focus of LeDeR was squarely '*aimed at processes'* and there was '*not enough attention paid to the improvements that could/should be made following a persons LeDeR review'*. There was a unanimous acknowledgement that '*the way we do things locally now is far better'* and that '*by having ****** as the LeDeR coordinator she has brought together all stakeholders and is making LeDeR everyone's business, but we know we need to keep improving'.*

- The removal of the Multi Agency Review (MAR) as part of the LeDeR process was seen as a '*seriously negative step'* as colleagues felt that '*nuanced gems were missed through its removal'*. Another person said that they '*have yet to meet anyone who didn't see the value of the MAR process'*

- There was some discussion around revising the LeDeR process to '*make it less cumbersome and more sustainable'*, for example one person suggested: '*I think the tools used to complete the LeDeR process could be embedded as part of Patient Safety processes'.*

- There were opinions shared about LeDeR requiring a '*continued national focus and effective leadership'* and '*if the focus ever shifts away, it will require more effort locally to ensure reviews remain a high standard*'. One person said that (the LeDeR process) *'requires continued national support to make it sustainable'*. Another person explained that we should '*do what other mortality reviews have done and make LeDeR reviews a legal duty*'. Other people believed that '*it should be mandatory to report on the deaths of people with a learning disability'* rather than saying that it is good practice to do so.

- In terms of ensuring information and improvements (i.e. the need for improvements) the focus group invited views on the need for greater awareness raising about LeDeR and importantly health inequalities, with respondents commenting 'we have *various methods for sharing information'* some of these included '*online platforms'* and things like '*regular newsletters'*. Colleagues shared that that '*we now have some great teams in our hospitals supporting people with a learning disability and their families*'. A brief discussion the use and understanding of Annual Health Checks (AHC), hospital passports and Health Action Plans (HAP) followed. There was a sense from colleagues that they believe for example: '*more formal mechanisms are required with these',* with additional comments like '*we know that some people have them and others don't and that's not right*' and '*unless they are mandated, they will remain as good practice tools, and this will continue to return inequalities'.*

- Examples in narrative was given by focus group participants to highlight to the review team that there is clear evidence that HAPs and AHCs are '*regularly audited'* and, that a form of '*thematic analysis'* was in place alongside respondents talking about always being '*encouraged to offer ideas about how to make improvements'.*

- The focus groups heard about an audit undertaken around Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) and there was evidence to suggest this had been applied inappropriately in some instances. As a result of this learning, this had been addressed and changes/improvements had been made to ensure that uses of the term 'Learning Disability' or 'Down Syndrome' were not used as a reason to apply a DNACPR order.

It is noted that in relation to the latter comment, the review team examined nationally benchmarked data for North Bristol trust (NBT) submitted as part of the annual learning disability improvements standards exercise. This data showed that the last two years of data (20/21) illustrated positively that DNACPR at Southmead hospital was lower than the national average.

- All respondents shared a view that they are expecting to undertake the Oliver McGowan mandatory training and all respondents were supportive of the training. There was recognition that '*more awareness'* of both learning disability and autism should be carried out for pre-registration nursing and also within GP and other disciplines training, given that '*these topics are not part of core clinical training'.*

- There was a clear sense from participants that there needs to be a level of standardisation if different organisations are to continue to deliver different types of training. One colleague commented: *'There are innate risks if quality and content is not assured or consistent'.*

- It was felt that the '*Oliver McGowan mandatory training will go some way to address the inconsistency and variance in training'*, but there were also concerns raised that it was going to be *'incredibly* difficult *to ensure the entire workforce were able to access and complete the training'* given the pressures the workforce face.

- It was also noted by one participant that '*Oliver's mandatory training will help to raise the confidence of clinicians and other members of the workforce'* going onto say '*especially those who do not regularly have contact with people with a learning disability or autistic people and their families*'.

- In relation to the theme of workforce, the review heard how the ICB have a Trainee Nurse Associate (TNA) Programme which is now embedded and working well. Given the workforce challenges across the NHS this was reassuring to note and will ensure that the right people with the right knowledge and skills are recruited to support people.

- The focus groups were informed of the Acute Liaison Nurses and Learning Disability Champions within the local system and how their intervention and support is starting to make a real difference within the Acute Trusts. However, all participants readily acknowledged how this is only one small part of what the system needs to do to improve how they perceive, respond to and care for vulnerable people.

- The review team explored how local flagging systems were operating and were informed that the Acute Liaison Service has a good flagging system which ensures that they know when a person with a learning disability is admitted to hospital. However, it was commented

that '*these systems on their own are by no means fail-safe'* and that *'we need to continue to use the high-quality learning from when things go wrong, if we're to prevent future harm'.*

- Alongside this, the group heard how Acute Liaison Nurses have developed effective relationships with colleagues in local community learning disability teams, GP surgeries and within 3rd sector community providers. These connections are ultimately ensuring that people (and their families) receive a better and more seamless level of service. One example that was given was how the Community Learning Disability Teams now in-reach into local hospitals once someone is admitted. Another example was the 'follow-up' (outreach) provided by the Acute Liaison Service to ensure people remain well after they have left hospital.

- Consistent with the national picture, for those individuals who may not otherwise be known (by prior involvement) to learning disability or autism services, peoples self-reported experience of accessing primary and acute care services suggests considerable variance in the quality of care they receive.

- The focus group heard how Primary Care (GP surgeries) '*always do their best'* to flex in how they respond to people. It was also noted that given the current pressures, people are '*being supported to attend their GP practice when they need to*', and if a person doesn't need to go to hospital, *'people can come to us whenever they need us, they don't need to go to A&E'.*

- There was conversation amongst the groups around children and young people (CYP) who also have a learning disability, are on the autistic spectrum or both. There has been '*a noticeable increase in CYP turning up to A&E in crisis'* and it was noted that, '*locally, the right resources weren't always readily available'*. It was discussed how the CYP challenges across the NHS and social care will require ongoing investment and directed support.

- In discussing the support needs of people and families and what needs to be done, participant comments include that '*there needs to be a system shift towards supporting people well in the community'* and *'for this to happen there will need to be significant reinvestment'.* One participant noted that '*community services need to be of much greater quality as, one of the unintended consequences of the Transforming Care policy is that it has in some cases effectively re-created mini-institutions in the community'.*

- In discussing pressures on the acute hospital system one participant commented that they believed the recent increases in A&E attendance was '*partly influenced by the impact of the*

pandemic and the lasting emotional distress this is/has caused children and young people, particularly those who are autistic or who have learning disability'.

Appendix 7

The BASS quality check feedback

The feedback below covers a range of themes/points, along with some direct quotes from members of the quality checking team.

- The ED had a well-spaced waiting area, and an Autism welcome

  poster was being used.

- There were no separating screens for privacy or dignity.
- There were no autism alerts on records the checking team reviewed.
- For ambulance check-ins, there was no way to access/add information, which may miss critical information.

- The ‘Bags of calm’ (which include things like lights, sensory fidgets, gel squeegees, noise cancelling headphones, ear defenders, ear plugs, weighted blankets or lap pads, essential oils/smells – lavender/orange, Dark glasses/visor for light sensitivity) which were available for autistic/vulnerable people were felt to be a really good idea, but there may be a dignity issue in asking for one of these.
- The volume of posters on display across the E.D was difficult to process.
- Upon seeing the autism diagnosis reception staff offered a quiet space/room.

However, one quality checker offered the following feedback:

“It was great they were able to find a quiet space for me to remain calm with my noise cancelling headphones. But then they forgot I was in a quiet room, and I missed my place in the queue”

- The receiving staff/clinicians adjusted care to suit different ages/gender.
- There was effective adherence to maintaining people’s dignity and privacy
- Some areas of the service had stickers under light switches to notify people of the dimmer function
- It was really positive that autism awareness training was co-produced.
- The ‘Move Makers’ (these are hospital volunteers who help signpost people throughout the hospital) and Security had received autism training.
- We observed good evidence of ‘reasonable adjustments’ resources but would suggest these are placed in every area throughout the hospital.
- There needs to be more in-depth tier 3 training needed for colleagues in the psychiatric admissions team.
- The pressure of time for the psychiatric admissions team may mean that autism passport/reasonable adjustments could be missed.
- There are some constraints in being able to always offer quiet spaces
- Some leaflets were out of date and need to be reviewed.
- It would be helpful to have some information about where to get help if you are not admitted.
- There appeared to be a split in the consistency of psychiatric admission team & the out of hours team.

"When I needed a mental health assessment, I saw the South Glos' out of hours crisis team after 7 hours in ED. They gave advice that wasn't followed by my local crisis team. "I found it really distressing, and was left without support, and this caused a further deterioration in my mental health"

Appendix 8

The Brandon Trust quality check feedback

The Quality Check aimed to explore a number of themes within the hospital in order to learn how a person with a learning disability or autism would experience the physical environment, how their needs and choices are responded to, and the quality of healthcare they could expect. The feedback below covers a range of these themes/points, along with some direct quotes from members of the quality checking team.

- Arrival at the hospital is made easier by the Move Makers who are a team of volunteers who meet, greet and direct patients and visitors arriving at the hospital building and carparks. They were easy to spot due to their bright pink shirts and were warm and welcoming.

- Certain receptions were designed in such a way that people using wheelchairs couldn't be seen and receptionists had to stand and lean over the desk which made people feel uncomfortable.

- One receptionist explained that they would usually speak to the carer rather than the person themselves, whilst others said that they would speak more slowly.

"***I felt like they were judging us. Everyone is different. I think they underestimated what we can do".***

- It was highlighted that there were not enough disabled parking spaces.

- There is not always clear information about the patient's learning disability or autism and associated needs on referrals from consultants and doctors which can lead to difficulties for the patient and other healthcare staff.

- Some signage was too small to read.

- There were some very good examples of how the environment had been made more inviting for patients and visitors. The garden was felt to be a '*brilliant space'* for people to relax and unwind in.

- The Fresh Arts Team is an excellent idea and the man playing the piano brought about feelings of calm and peacefulness.

- There are a range of Learning Disability Champions who, when questioned, showed a great wealth of knowledge.

- It was felt that there may be an over reliance on Learning Disability Champions. As they do not operate 24/7 in the hospital, there will be occasions when someone is admitted and they are not around to support.

"an individual's experience may really vary dependant on the time they are admitted, or dependant on how busy the learning disability nursing liaison team are. We believe individuals should be able to access a good standard of care no matter what time they are admitted".

- Some staff explained that they had not yet received training in learning disability or autism. The Learning Disability Team assured us they are aware and are taking steps to address this.

- The understanding of the Mental Capacity Act (MCA) and best interest amongst the hospital staff that were spoken with appeared to be good.

- Most of the staff appeared have a good knowledge of reasonable adjustments, and some of the departments went the '*extra mile'* to ensure people were given the information they needed, in a way in which they understood, and that they had the right preparation and support when in hospital.

"We thought the staff in theatre and the medirooms were doing really great work to ensure patients have a named nurse and that everyone involved is made aware of reasonable adjustments needed throughout the period of surgery, recovery and aftercare".

- Referrals for outpatient appointments did not always reach the Learning Disability team.
- There is a lot of reliance on staff (particularly co-ordinators) remembering to flag the learning disability team when someone with a learning disability or autism is coming into hospital.