

Learning Disabilities Mortality Review (LeDeR) Annual Report

1st April 2022 to 31st March 2023

**Learning from deaths of people with a
learning disability**



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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 completed 100% 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.

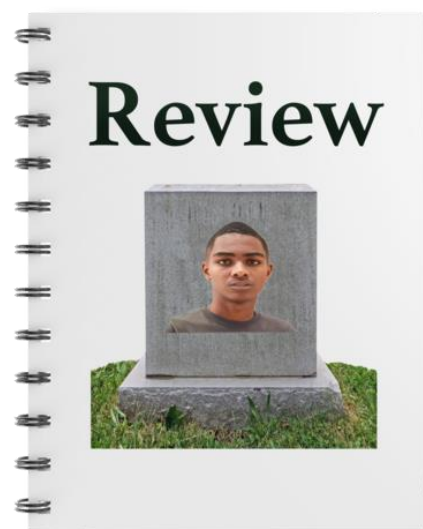
The main purpose of the LeDeR review is to:

- 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.

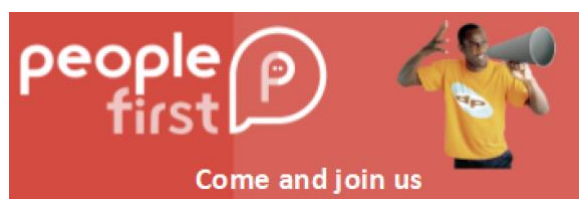
Sirona has taken on the support meetings for their reviewers, through having a safe space to raise any concerns or speaking to other reviewers as to how they might approach a situation.

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

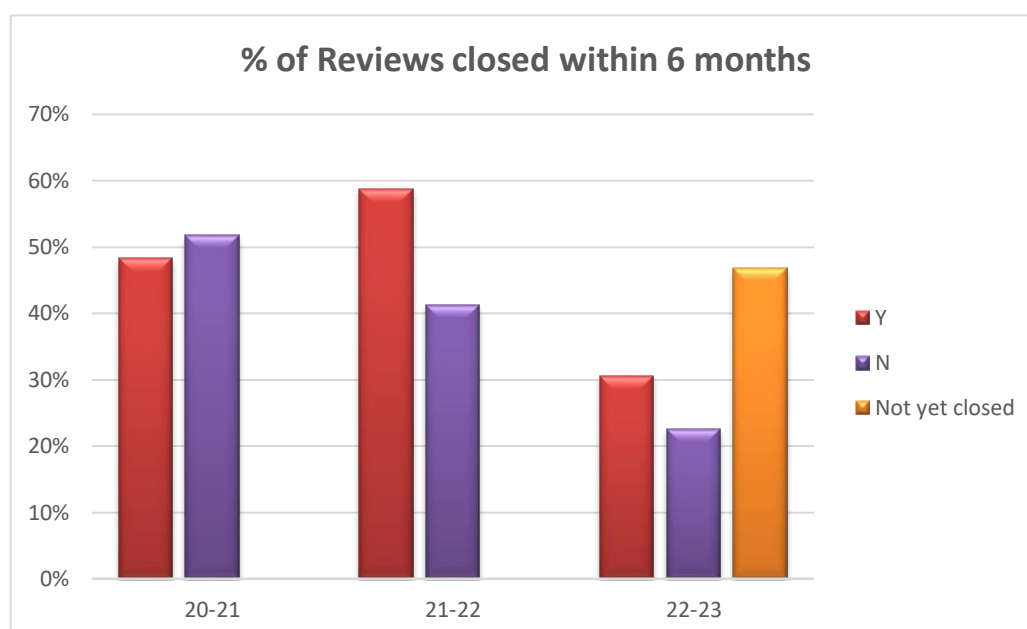
In January 2022 NHSE introduced LeDeR reviews for autistic people who do not have a learning disability. Since January 2022 to 31st March 2023 two ‘autism only’ deaths were notified to BNSSG. Both were suicides that have been reported and investigated through police investigation, Coroners inquest, Serious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

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
<ul style="list-style-type: none"> 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.
<ul style="list-style-type: none"> Although blind, family said their son had excellent supported living – with staff arranging regular massage, outings, church on Sunday, audio books etc
<ul style="list-style-type: none"> Excellent co-ordination of care and carers tailoring opportunities such as playing piano and taking him to recitals of classical music
<ul style="list-style-type: none"> Advocating on the person’s behalf with ambulance staff, insisting person was taken to hospital.
<ul style="list-style-type: none"> Many examples of the Learning Disability and Autism Liaison Team making timely assessments and supporting people in hospital which significantly improved their care
<ul style="list-style-type: none"> Staff fundraised to buy him a bike so he could visit friends and family independently
<ul style="list-style-type: none"> Good support from GP, Care staff went the extra mile to arrange visits to Pakistan despite having profound disabilities and a rare condition
<ul style="list-style-type: none"> Effective follow up from GP and primary care team when discharged from hospital
<ul style="list-style-type: none"> Lots of examples of collaborative working and involvement of family members
<ul style="list-style-type: none"> 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
<ul style="list-style-type: none"> 90% of reviews showed that people had their flu vaccine

<ul style="list-style-type: none"> • 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
<ul style="list-style-type: none"> • GP's regularly visiting Care Homes and building great rapport with residents and staff
<ul style="list-style-type: none"> • 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
<ul style="list-style-type: none"> • 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
<ul style="list-style-type: none"> • Poor transition to adult service, no CLDT as an adult, lack of support for carers
<ul style="list-style-type: none"> • Ensure sepsis guidelines are followed in hospital to identify sepsis in the learning disability population which may be overlooked due to diagnostic overshadowing
<ul style="list-style-type: none"> • 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
<ul style="list-style-type: none"> • Placement reviews need to take place regularly to ensure people are in an appropriate placement and accommodation that is suited to their needs
<ul style="list-style-type: none"> • Reasonable adjustment of taking blood from foot rather than arm as recommended by mother as son reacted if he saw the needle
<ul style="list-style-type: none"> • Checking learning disabled patients for pressure area injuries during prolonged hospital stays
<ul style="list-style-type: none"> • Training/awareness for residential staff identifying vital signs and when to refer to End of Life and Palliative care services for guidance and advice
<ul style="list-style-type: none"> • Delays to putting DOLs in place whilst people were in hospital
<ul style="list-style-type: none"> • Carers assessments to be completed for those living with a family member
<ul style="list-style-type: none"> • 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 spicy food fans with regular curry nights in the home. Some people were staunch meat and two veg, enjoying 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.

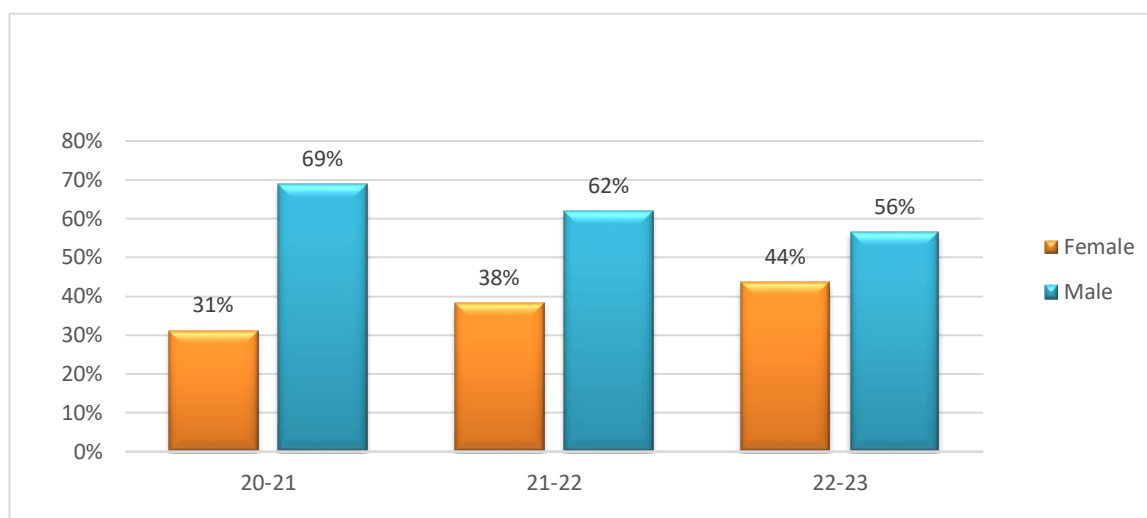
Demographic data

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

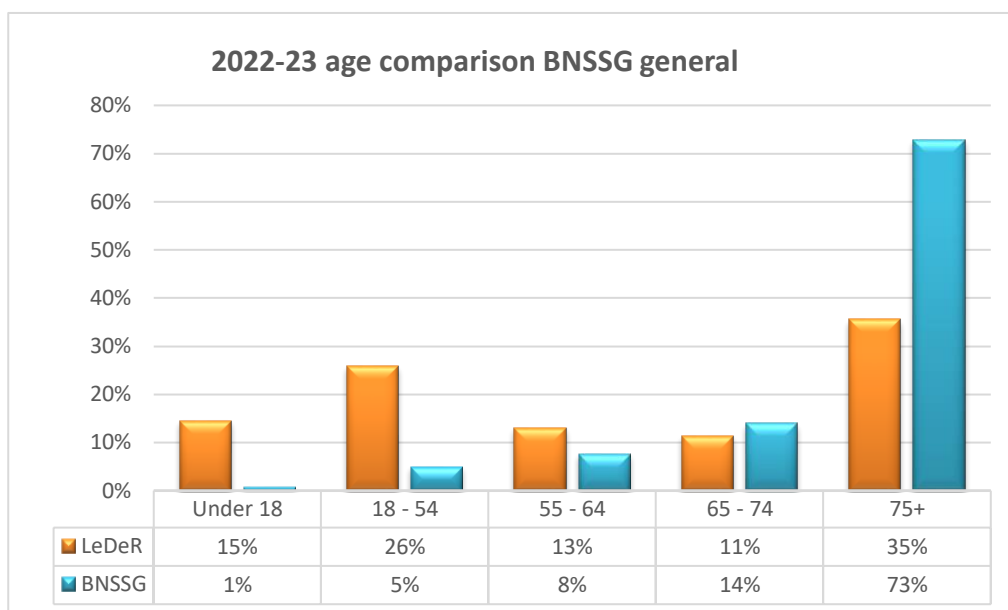
Reviewing the comparative data men with a learning disability live slightly longer than women with a learning disability but die 12 years younger than the general BNSSG population. However people with learning disabilities in the BNSSG population generally live 6 years longer than the learning disability 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>

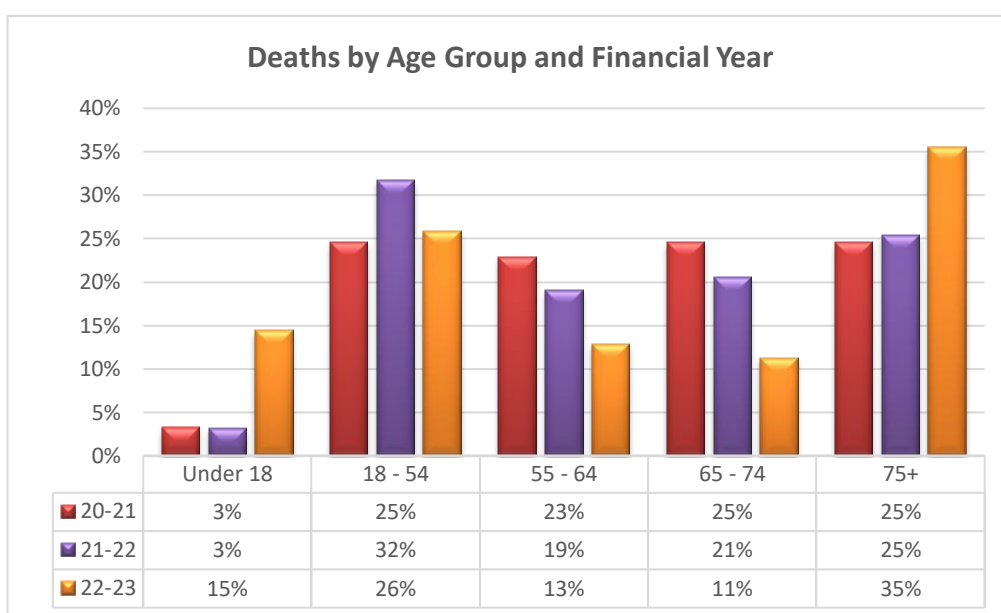
The majority of learning disability deaths (35%) were in the over 75 age group, an increase in age of death from last year showing many people with learning disabilities in BNSSG are living longer (Graph 4). However the spread of deaths throughout all age groups for people with learning disabilities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



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



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.

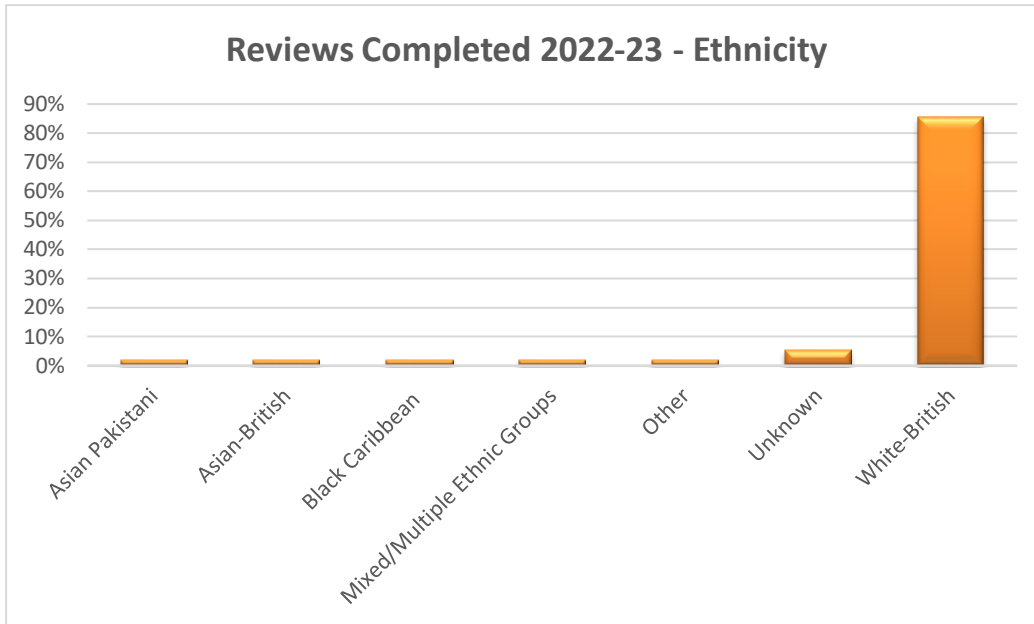
The project report published in January 2023 identified issues and made recommendations to support the Healthier Together vision for people with learning disabilities and autism from all communities to access high quality, fully integrated care that meets their expectations of services. We wanted to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

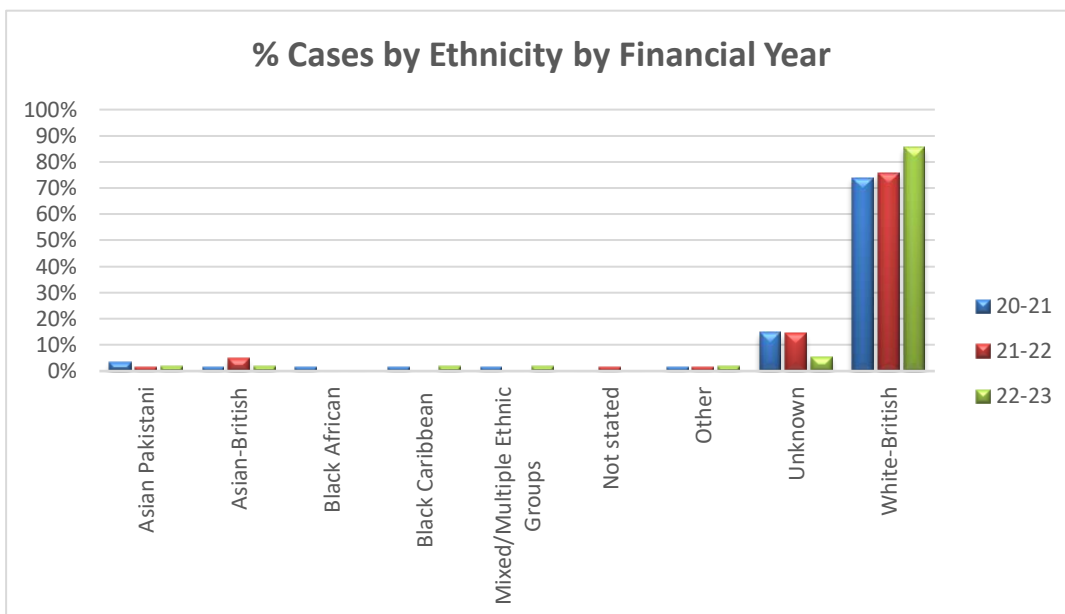


L-R Nura Aabe, Founder Autism Independence, Rosi Shepherd CNO, Aga Kowalska - Autism Independence, Shane Devlin, CEO BNSSG

Graph 6 – Number of completed cases by ethnicity



Graph 7 – Completed cases by ethnicity – year comparison



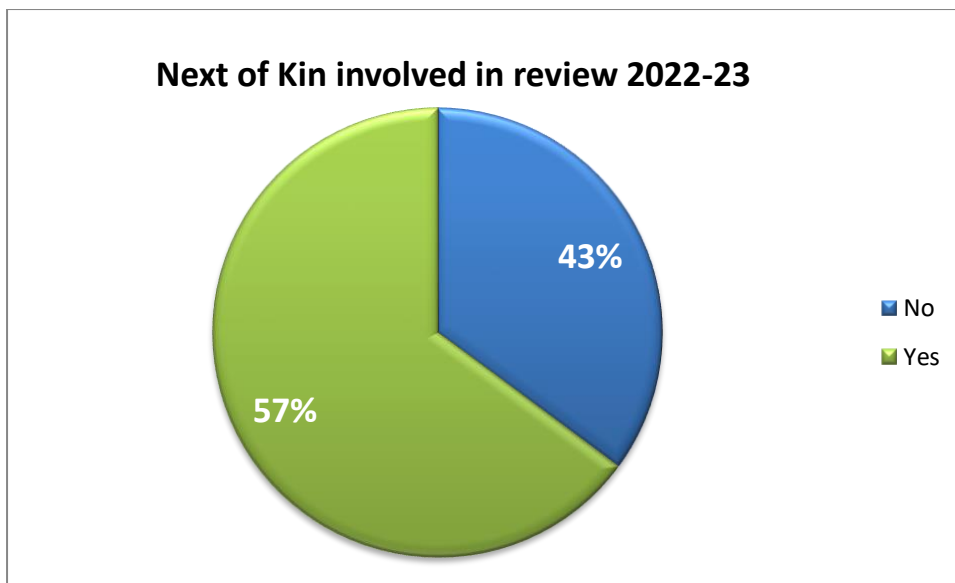
	20-21	21-22	22-23
Asian Pakistani	2	1	1
Asian-British	1	3	1
Black African	1		
Black Caribbean	1		1
Mixed/Multiple Ethnic Groups	1		1
Not stated		1	
Other	1	1	1
Unknown	9	9	3
White-British	45	47	47

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.

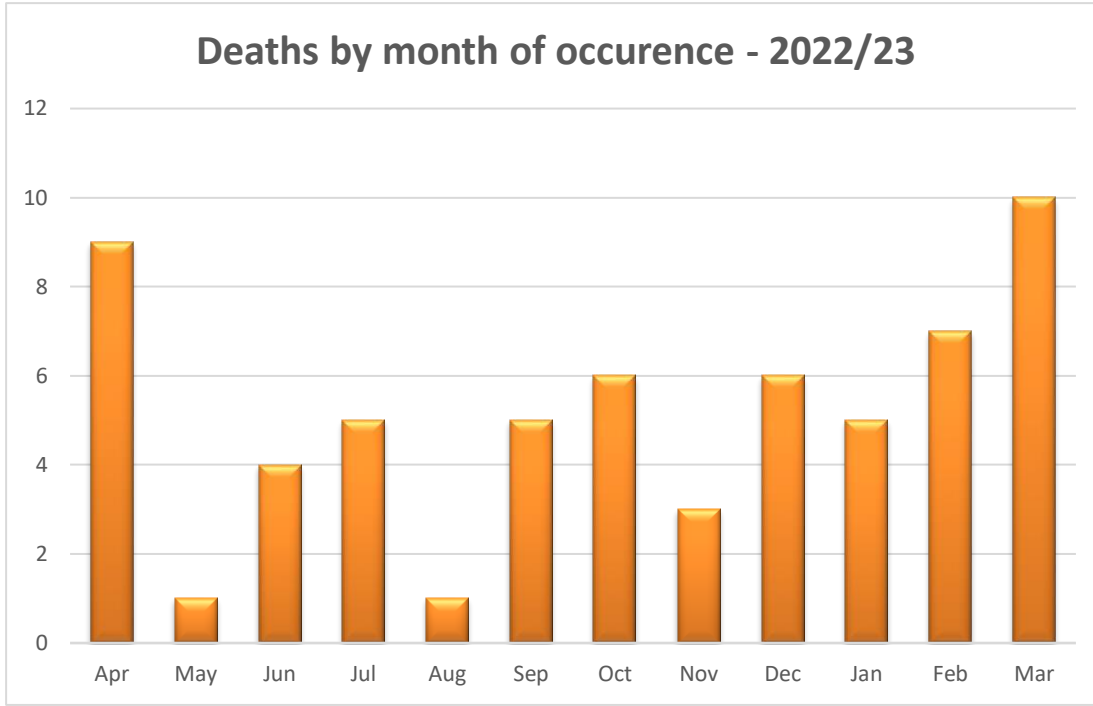
Graph chart 8



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

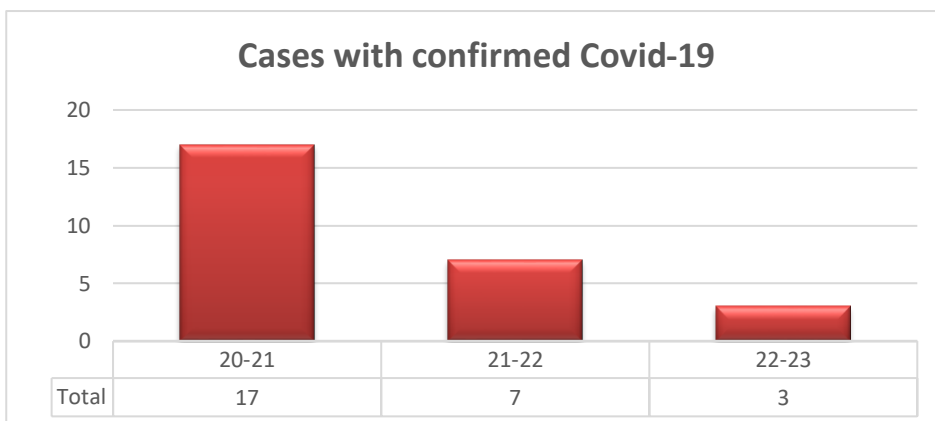


Cause of death

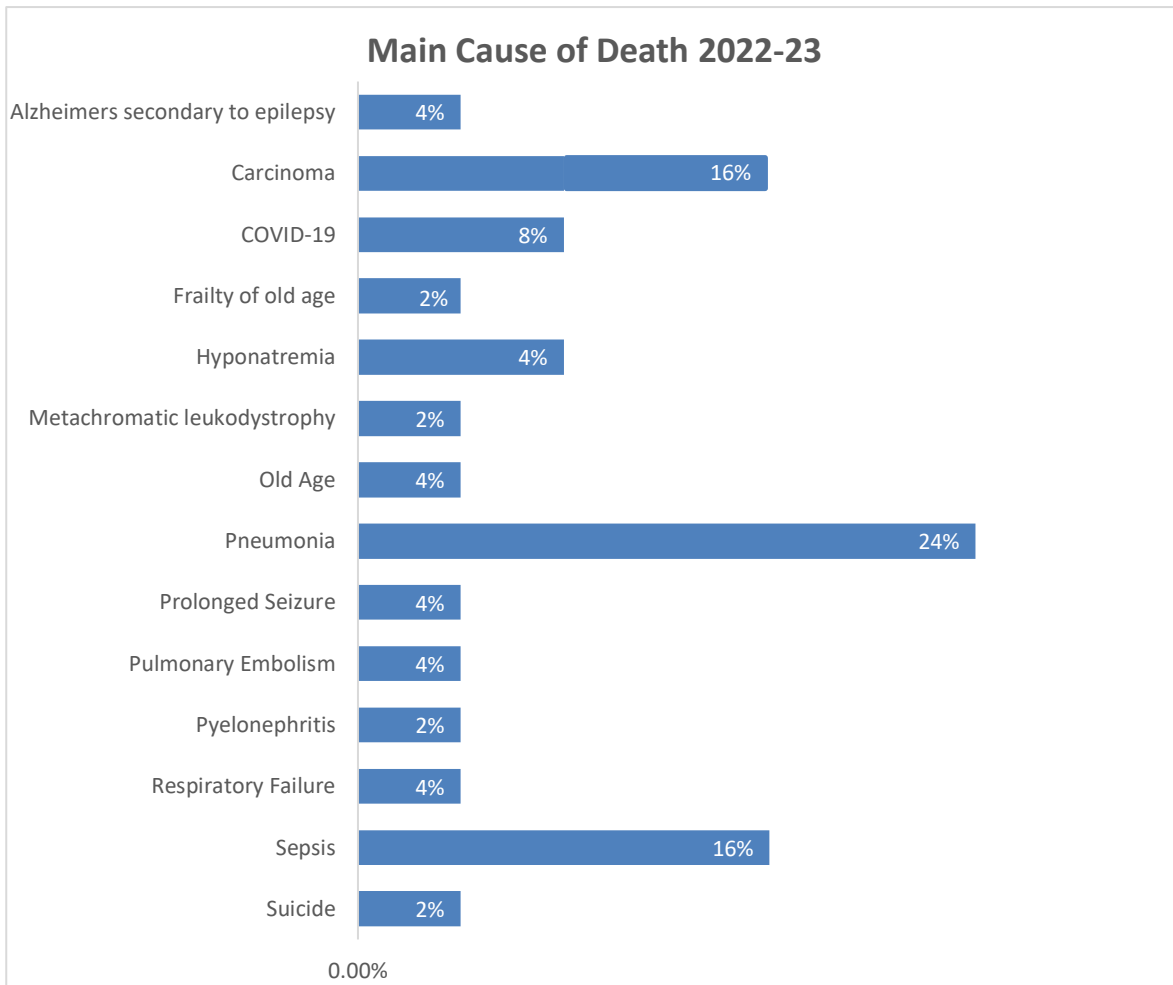
The reviewer records the cause of death in the review as detailed on the person's death certificate. From the completed reviews, 23% of deaths were related to pneumonia as the primary cause.

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



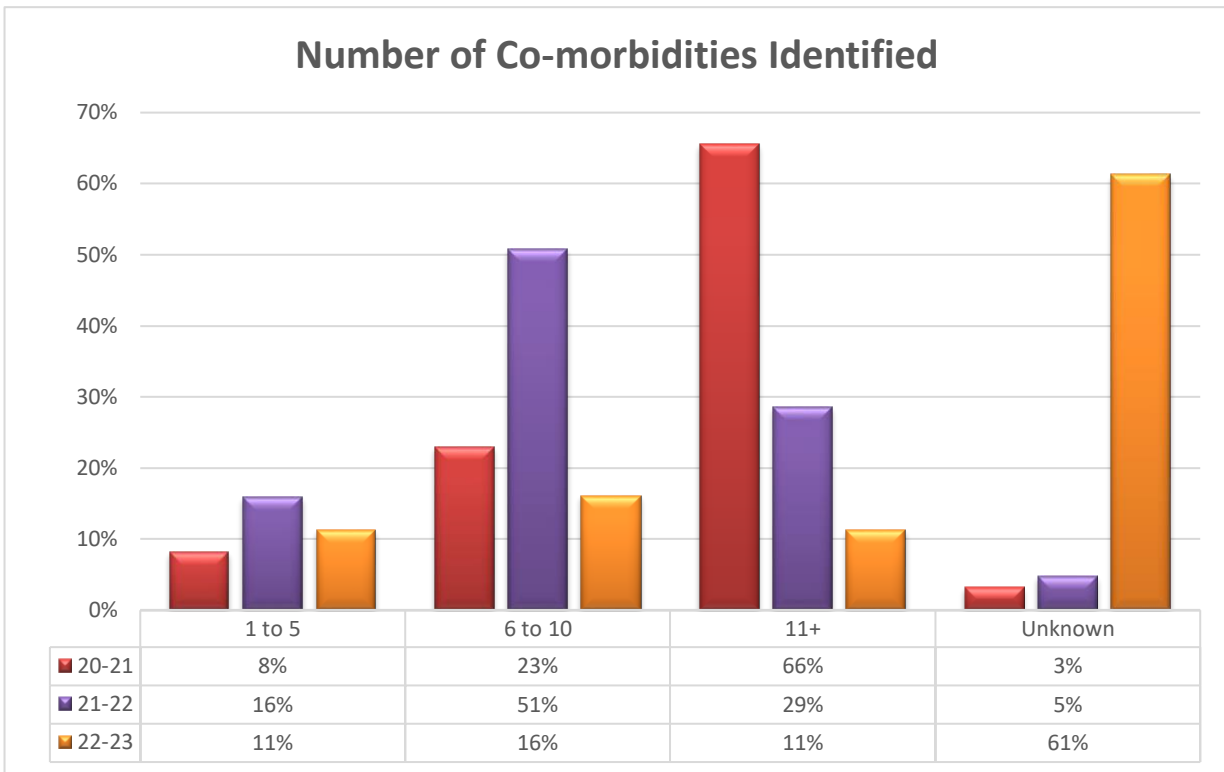
Graph 11: Main causes of death



Graph 9 - Number of co-morbidities

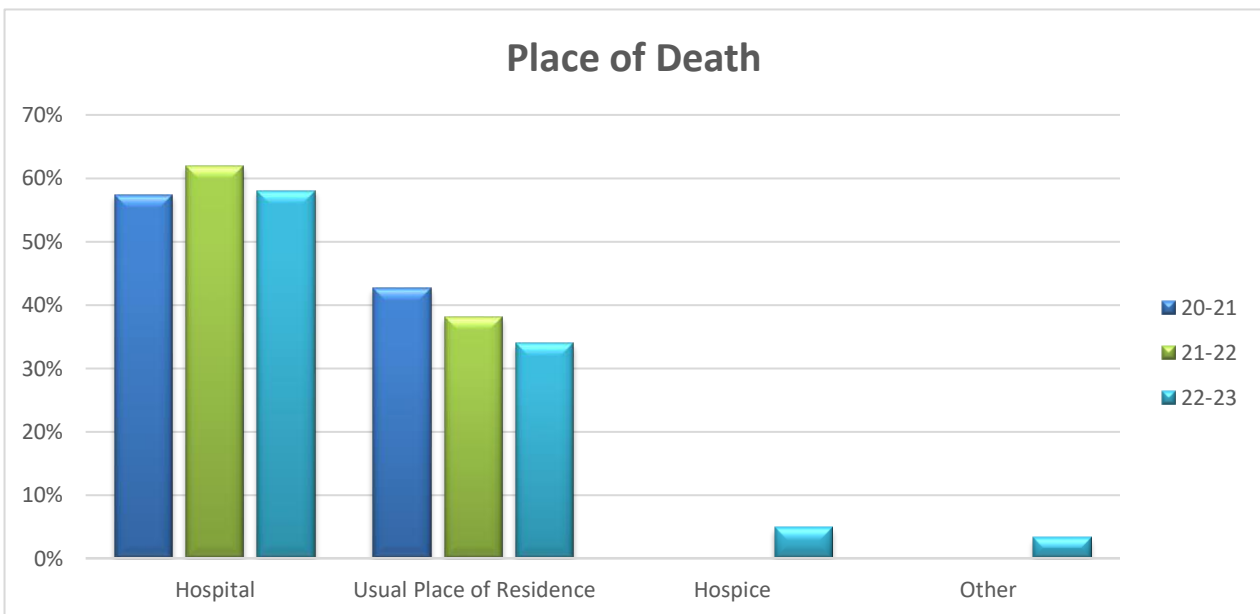
Every person in the reviews had one or more co-morbidities. However the design of the new national forms does not ask reviewers to detail co-morbidities in the review. This has made it difficult this year to collect comparison data on co-morbidities with 61% of reviews unknown. The highest number of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



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.

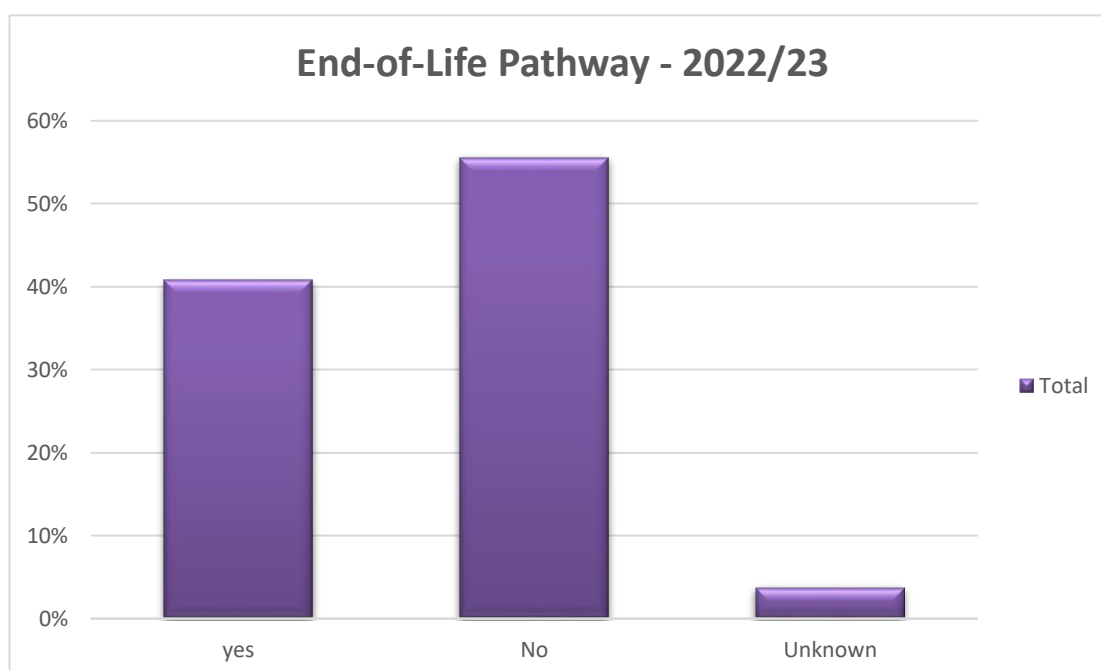
End of Life

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 popular choice.



Graph 11: End of Life care pathway

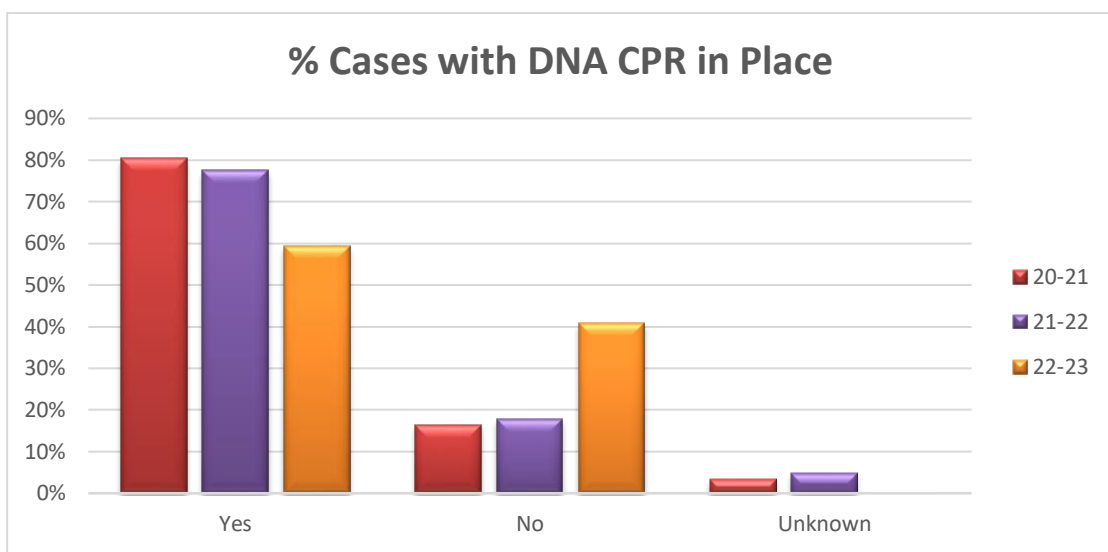


Support for End of Life Care:

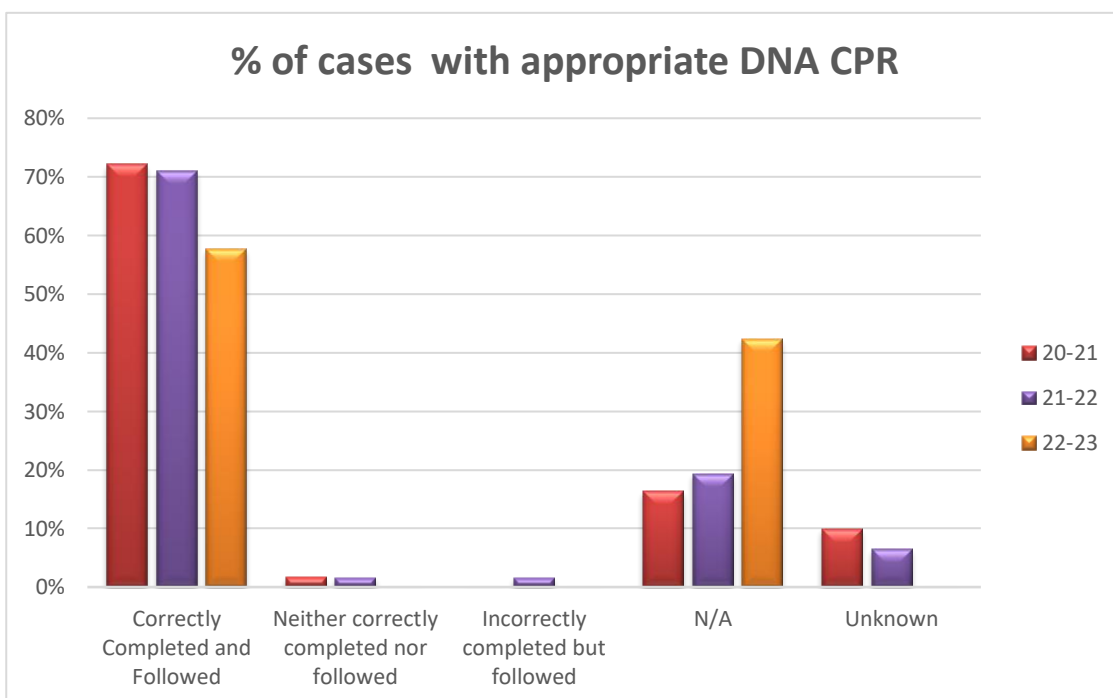
Across residential and support services staff are passionate about the people they supported, wanting to ensure that they were able to continue to support them throughout their life, including at the end. Most homes had no training in providing end of life care even though they were supporting older 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 an 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.

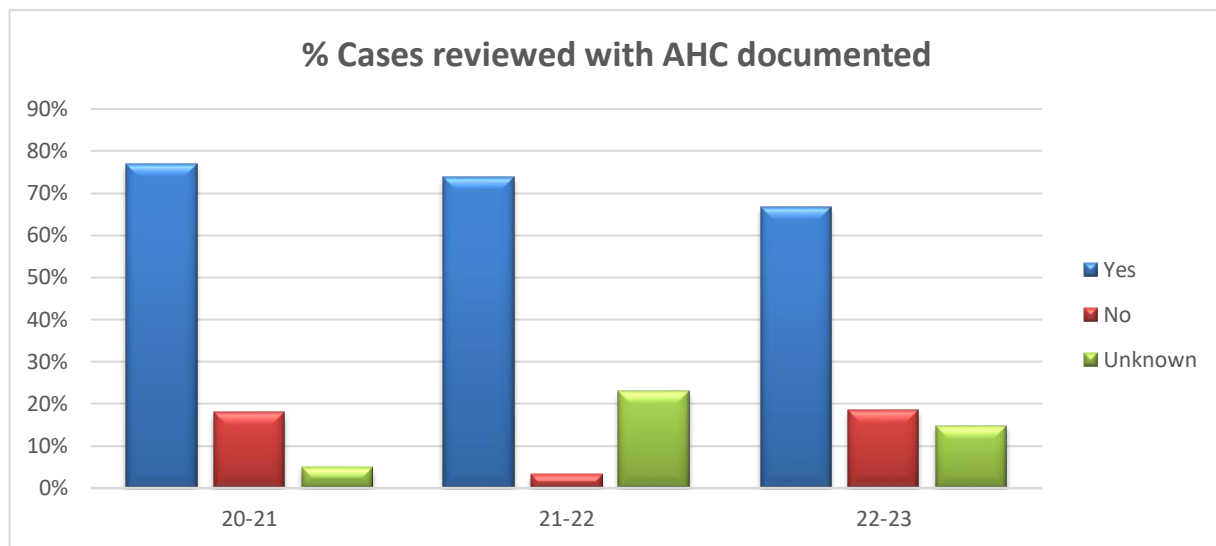


We continued to develop a toolkit of AHC resources to support GPs & practices, validated by Community Learning Disability Teams on the AHC portals hosted on GP platforms – Teamnet/Remedy, including easy read resources on a range of topics.

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 completed 100% 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 Health 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 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.

Health Action Plan
Developed and designed by people with learning disabilities

My name is **Dave Smith** Date **14 July 2022** D.O.B **9/4/1974**
 In case of emergency Name **John Smith** Phone no: **01234 567890**

Key information about me

	Actual	Goal/Target
Weight / BMI	82kg	78kg
Blood pressure	140/86	128/75
Dental check		
Eye test		

For the GP to complete: existing health conditions being monitored.
Diabetes – monitor sugar and carbohydrates
 Reduce carbs to 200gms per day

My 3 Big Goals for the next year are

Goal 1 Drink more water, 8 glasses a day (2 litres)

Goal 2 Lose a little weight (see target above)

Goal 3 Start one new activity

For GP to complete in discussion with patient. Additional comments / health checks e.g. hearing test, flu jab / covid vaccination
Hearing test within next 6 months, Flu jab in October

Who is responsible? _____ Target Date _____

Developed in partnership with Brandon Trust
 Bristol, North Somerset and South Gloucestershire Integrated Care Board

My 3 big goals for the next 12 months

1 To drink more water

To improve my health I want to achieve the following outcome/goal
 To drink 6-8 glasses of water every day

To achieve this goal, I will take the following action
 Make and keep a glass chart with stickers

To achieve this goal I will need the following support
 Buy a water bottle

My progress we will review in _____
 What, when, how, who?
 Mary, support worker, weekly check

2 Drinking water is so important for your health

Remember to brush your teeth twice daily

3 Have a fresh veggies day

Goal 1

To achieve this goal, this is how I will celebrate...
 Celebrate at the _____

Developed in partnership with Brandon Trust
 Bristol, North Somerset and South Gloucestershire Integrated Care Board

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.

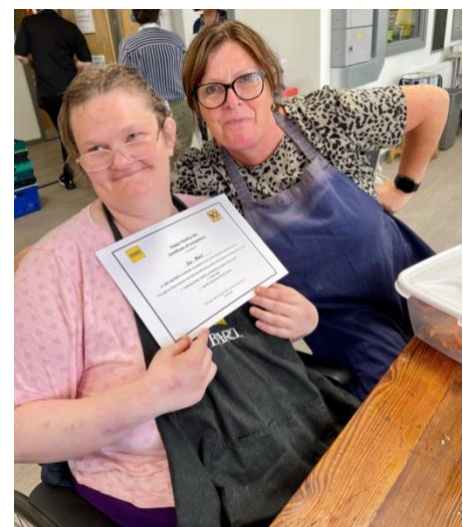
Our 'Healthy Me' cookery school has addressed obesity and diet for people with learning disabilities in partnership with Square Food Foundation and housing/support providers, Milestones and Brandon. We wanted to encourage people to make connections between what they eat and their health. The first students 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.






Swallowing awareness

15% of people with learning disabilities have Dysphagia




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Common signs of dysphagia;






-  choking or gagging on food 01
-  Coughing, during or after eating or drinking 02
-  Excess saliva, dribbling & spitting out food 03
-  Going red in the face or watery eyes when eating or drinking 04
-  Gurgly wet sounding voice after meals 05

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

-  Good eating position – sit up straight with feet on floor 01
-  Keep an upright position 30 mins after eating 02
-  Plenty of water and sips during meal 03
-  Eat slowly with small bites. Don't put too much in mouth 04
-  Supervised meal and avoid talking while eating. 05

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

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 (BuLT) 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.



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 BEFORE APPLYING.

Course content

- 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.
- 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.
- 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?
- 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?
- 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.
- 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.
- 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?
- 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 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	30 th May	1.30pm - 4 pm
Tuesday	6 th June	1.30pm - 4 pm
Tuesday	13 th June	1.30pm - 4 pm
Tuesday	20 th June	1.30pm - 4 pm
Tuesday	27 th June	1.30pm - 4 pm
Tuesday	4 th 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.

Project overview

Working directly with autistic service users, and in partnership with Trusts, we developed an autism access audit tool which was applied to four Emergency Departments across the ICB. We then interviewed psychiatric admissions, and the LD & autism liaison teams to develop a set of recommendations.

I felt the understanding of autism had changed significantly in the last 10 years, particularly in relation to presentation in women

Ruth

Hospital Emergency Department (ED) audit findings

- Most had well-lit waiting areas
- No staff awareness of autism – especially reception staff
- Lack of separating screens for privacy or dignity
- Autism alerts not on medical records/bed
- 'Volume' of too many posters on display
- Noise and stress variable depending on time of day
- Autism welcome poster was being used in some locations

Recommended actions for hospitals

- Account for different perspectives with dignity
- Autism awareness training – co-produced with autistic people
- Autism training for 'meet & greet' volunteers
- Promoting use of autism awareness & flag on patient records
- Develop 'waiting problem' form for new-visit patients
- NHS/IAS autism audit tool
- Pages for people in quiet rooms
- Reasonable adjustment resources in every area

Reasonable adjustments - Actions for trusts

- Purchase of resources to support reasonable adjustments
- Bags of Calm (i.e. lights, sensory fidgets, gel squezers)
- Essential channels/telemedicine
- Noise cancelling headphones, ear plugs
- Weighted blankets or lap pads
- Other dark glasses/visor for light sensitivity
- Stickers to show dinner switches for lights
- Stickers for alert to charge tablets/phones
- Use of augmented communication tools

Next steps

- Tailored recommendations for each ED with feedback sessions for staff
- Support purchase of reasonable adjustment resources for Trusts with a recommended shopping list
- Present findings to Health Providers Network
- Establish programme for Children's hospital audit with parent/carer
- Amend audit tool for Children's hospital
- Share audit tool & findings at regional meetings to promote good practice throughout region

Ben S

It was great that they were able to find a quiet space for me and had noise cancelling headphones. But then they forgot I was in a quiet room and I missed my place in the queue

For more information contact:
Lesley Le Pine - Associate LP Projects
NHS Bristol, North Somerset & South Gloucestershire ICB
Mobile: 07785 95253 | Email: lesley.lepine@nhs.net

NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board

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.



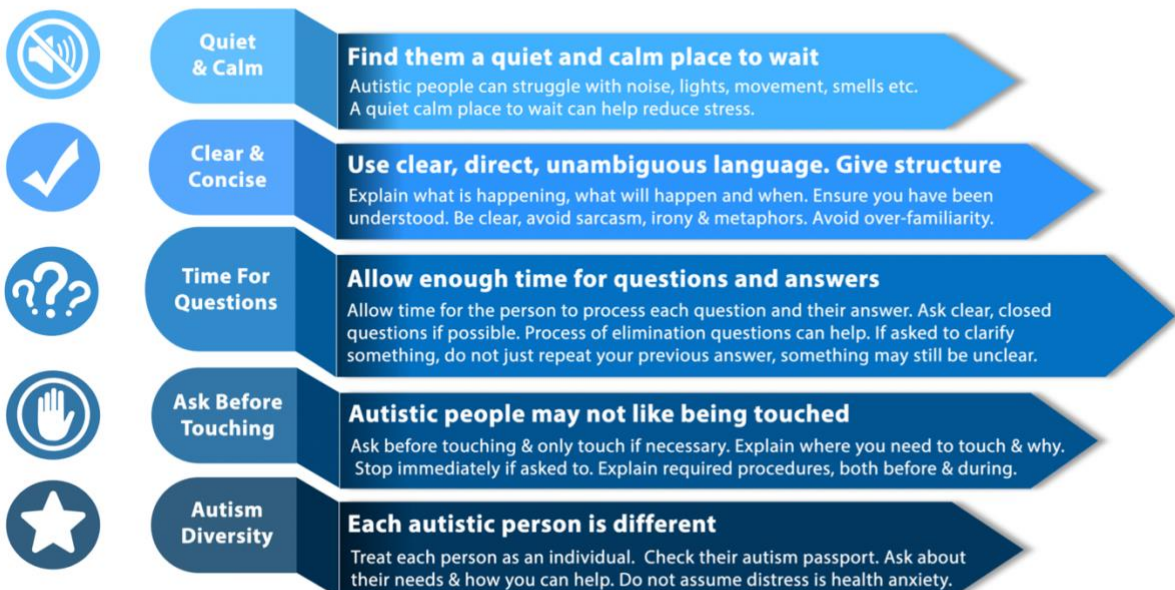
Similar to 'Question Time' events, meetings will be held 2-3 times a year, for autistic people to meet leaders of health organisations, city councils etc. Meetings will be themed on issues such as hospital access, support from GP's, transport, police, etc where people with lived experience can share 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

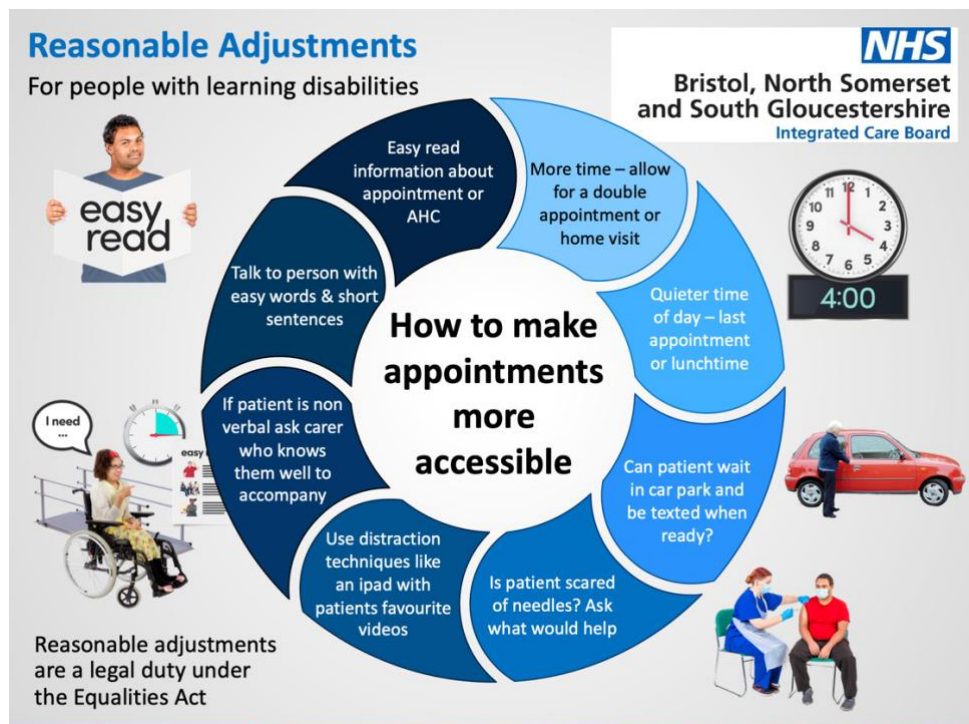
Through the ED audits undertaken by autistic people the group produced an autism flier for staff which had 5 top tips for supporting autistic people who come to the Emergency Department. People in the group had experiences being treated in ways which exacerbated stress level especially when people were 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 For Autistic Patients

Possible adaptations that can help



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 symptoms 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



The logo for Milestones Trust features a teal-colored curved line above the text. The word 'Milestones' is in a dark blue, sans-serif font, and 'Trust' is in a teal, sans-serif font.

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.



March- 2023

People First - Supporting adults with Learning Disabilities and/or Autism

People First Activities - Bristol and South Gloucestershire.

☕ = Speaking Up Group 🍵 = Friends Together

Monday	Tuesday	Wednesday	Thursday	Friday
		☕ Yate Bolero Lounge, BS37 4AX. 10.30-11.30 With Joseph		☕ Bristol BS1 Central Library, BS1 5TL. 10.30am-12.30. With Kirsty & Joseph
☕ Bristol BS9 Coffee One, BS9 4LP. 10.00-11.00 With Joseph	☕ Kingswood Centre, BS15 4PS 10.30am-12.30. With Kirsty		☕ Bristol BS1 Boswells (General), BS1 3XB 10.30-11.30 With Kirsty	☕ Bristol, BS3 Bedminster Library, BS3 4AQ. 10.15-12.15 With Kirsty
	☕ Patchway Coniston Community Centre, BS24 5LP. 11am-1. With Kirsty	☕ Bristol BS9 Westburg Park Church BS6 7QB. 12.30am-2.30. With Kirsty		☕ Bristol, BS3 The Tobacco Factory, BS3 1TF. 10.30-11.30 With Kirsty
	☕ Patchway Snack Attacks at the Park, BS24 5LP. 10.30- 11.30 With Kirsty	☕ Kingswood The Park Community Cafe, BS15 4AR 10.30-11.30 With Kirsty		☕ Yate Ridgewood Centre, BS37 4AF 11.30-1.30 With Kirsty

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



Activities in North Somerset

- ☕ = Friends Together 👟 = Walking Group
- 🗣️ = Speaking Up Group 👩 = Women's Wellness 👨 = Men's Wellbeing



Monday	Tuesday	Wednesday	Thursday	Friday
	27 Feb	1	2	3
	☑️ Walking Group - Weston Grand Pier to Clarence Park, 2pm			☕ Friends Together Clevedon Salthouse, BS21 7TY 10.30am to 12pm
6	☑️ Walking Group - Clevedon Marine Lake to Clevedon Pier, 2pm	8	9	10
		🗣️ Speaking Up Weston The Campus, BS24 7DX 11am to 1pm		☕ Friends Together Portishead Hall & Woodhouse, BS20 7FP 10.30am to 12pm
15	14	15	16	17
	☑️ Walking Group - Weston Grand Pier to Kingstone, 2pm	🗣️ Speaking Up Portishead The Beacon Hub, BS20 6EH, 11am		☕ Friends Together Weston Can't Dance Coffee (Sovereign Centre), 10.30am to 12pm
20	21	22	23	24
	👩 Women's Wellness Women's Wellness The Campus, 10.30am	☕ Friends Together - Weston Museum Burlington Street, BS23 1PR 10.30am-12pm	👨 Men's Wellbeing The Men's wellbeing Campus, 2pm.	
	☑️ Walking Group - Weston From The Campus 1.30pm.			
27	28	29	30	31
	☑️ Walking Group - Portishead The Marina, From Parish Wharf 11am			☕ Friends Together Weston Brewers Fagre BS23 1TT, 10am

To find out more Email us at info@nspf.co.uk or call the team on 01934 426 086



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.



