



LIVING WELL NEWSLETTER

Issue 4 February/March 2024

North Yorkshire and York

DOUBLE DISCRIMINATION: ETHNICITY, HEALTH AND LIFE EXPECTANCY

People with a learning disability from Black, South Asian (Indian, Pakistani or Bangladeshi heritage) and minority ethnic backgrounds face shorter life expectancy triggered by poorer healthcare access, experience and outcomes.

It has been reported at the recently published LeDeR (Learning from Lives and Deaths - People with a Learning Disability and Autistic People) 2022 report that the average age of death for people with a learning disability who are from an ethnic minority is 34 years, just over half the life expectancy of white counterparts, at 62 years of age.

There is not enough information on annual health checks for people with a learning disability from Black, Asian, and Minority Ethnic backgrounds.

A project is being developed by Learning Disability England and Race Equality Foundation

They want to do more work to help with the problems some people have with getting an annual health check. We want to think about issues to do with equality, race and culture.

They would like to make more information that is easy to understand. This could be things like leaflets and videos. This information will help to explain how annual checks work.

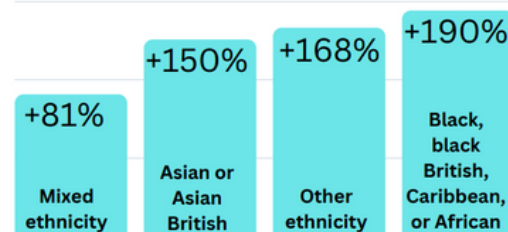
They want more people with a learning disability from Black, Asian, and Minority Ethnic backgrounds to know about health checks. This also means their friends, family, carers and wider support network.

You can find information on this project [here](#).

Please see the resources section at the bottom for links to relevant and accessible information .



% increased risk of dying earlier by ethnic minority group, in comparison with people from white ethnicity backgrounds, when adjusting for other demographic factors



LEDER 2022 REPORT



WE NEED TO TALK ABOUT ... EPILEPSY

Epilepsy is a condition that affects electrical activity in the brain, and this causes seizures. Nearly one in three people with a mild to moderate learning disability has epilepsy – and those with a severe learning disability or those who are autistic are even more likely to.

According to the Epilepsy Society, for many people, epilepsy is a condition which can be well-managed and has little or no impact on their life. For others, ongoing seizures mean that epilepsy has a long-term impact on them.

Like some other medical conditions, epilepsy is occasionally associated with premature death in some individuals, although this is not common. **SUDEP (Sudden Unexpected Death in Epilepsy)** is when someone who has epilepsy dies suddenly and no other cause of death can be found.

Please see the resources section at the bottom for links to relevant information and easy read materials on the on epilepsy and SUDEP.

EPILEPSY AND AGE AT DEATH

Epilepsy was the long-term condition that was most **strongly associated with dying at a younger age.**

This was followed by deep vein thrombosis, and degenerative diseases.

LEDER 2022 REPORT

USEFUL WEBSITES ON EPILEPSY AND SUDEP: JUST CLICK ON ICONS



OUR WORKING TOGETHER GROUP

Most of us are familiar with the idea of “Nothing About Us Without Us”. To make sure this happens, over the last 14 months, Inclusion North, have been organising lots of meetings for self-advocates with learning disabilities and/or autism, family carers, voluntary sector organisations and health and care professionals from across North Yorkshire and York.

During this time Our Working Together Group has developed an Agreement in how the Board and the group can work together to share decision making. Our Agreement with the Board states it's important to: **Feel welcomed, have good communication, be committed, be responsible, be valued and work together.**

Whilst this is just the start of working alongside the North Yorkshire and York Learning Disability and Autism Programme Board, and there are going to be several challenges ahead, changes are already being made to make sure Our Working Together Group attends the Board and is included. As a group we want to make sure that people with learning disabilities and/or autism and family carers can be part of the decisions made.

If you want to find out more about our Working Together Group please contact either hakan.durmaz@nhs.net or sandy.marshall@inclusionnorth.org

What we think is important when working together Nothing about us without us

Feel welcomed

- People should feel welcomed
- We will think about meeting spaces and people's access requirements.
- We will ensure everyone is included
- We will keep things simple to understand



Have good communication

- We will use easy to understand and accessible information
- People will have a voice
- We will listen to what is being said.
- We will let people know what is happening

Be Committed

- We are committed to involving people with lived experience and family carers.
- We think its fair to pay people for their time and transport costs.
- We are committed to developing skills and knowledge for health and social care staff and people with lived experience.



Be Responsible

- We will be responsible about the work we want to achieve.
- We will attend meetings and spread the information about working together.
- We will be open and honest about the work we are involved in.
- To make reasonable adjustments

Be valued

- Value the lived experience of people and their family members
- To involve people with lived experience and family members to educate health care staff.
- To involve people with lived experience and family members to quality check health services.



Work together

- We will work together to make health services better.
- We will work together with health care staff, other organisations, people with lived experience and family members .
- No decisions about us without us.
- The NHS is for everyone

HEALTH PASSPORT - AWARENESS TRAINING

This 90-minute online awareness session aims to increase knowledge and understanding of Health Passports (formerly known as Hospital Passports) and how these should be used by the person, their staff, family members and carers to identify their health and support needs, their likes and dislikes, how they communicate and any reasonable adjustments that they might need.



Training dates (choose one to book):

Tuesday 27 February 2024 @ 10.00am – 11.30am

Thursday 14 March 2024 @ 10.00am – 11.30am

Wednesday 27 March 2024 @ 2.00pm – 3.30pm

Thursday 11 April 2024 @ 10.00am – 11.30am

Tuesday 30 April 2024 @ 2.30pm – 4.00pm



INTRODUCING THE INTEGRATED QUALITY TEAM

As health and social care partners across Humber and North Yorkshire Health and Care Partnership and North Yorkshire Council we know how vulnerable the people you support are and will aim to work collaboratively to:

- Support the delivery of high quality care
- Prevent harm
- Share best practice
- Provide opportunities to influence and collaborate on and quality improvement.

The offer includes seven elements:

1. Training and Care Sector Engagement – sharing, learning and good practice
2. Leadership and Workforce support
3. Commissioning responsive supportive care
4. Digital Support
5. Effective Communication with and between providers
6. Joint working for system wide care and response
7. Recovery plans

Further information on our offer to the independent care sector, and how we can support your service can be found through [this link](#) or by contacting hnyicb-voy.yorkplacequalitynursingteam@nhs.net.



Our Aims and Values



Our Offer



INFORMATION AND RESOURCES

Double discrimination: Ethnicity, Health and life expectancy

- [The LeDeR \(Learning from Lives and Deaths - People with a Learning Disability and Autistic People\) Annual Report 2022 - Key Findings](#)
- [We deserve better: Ethnic minorities with a learning disability and access to healthcare - Race Equality Foundation](#) (including a video clip)
- [Healthcare Inequalities facing People with a Learning Disability from Black, Asian and Minority Ethnic Communities - MENCAP](#)
- [GP resources for Black, Asian and Minority Ethnic people with a learning disability - MENCAP](#)

We need to talk about ... Epilepsy

- [Information about Epilepsy - Epilepsy Action \(Easy Read\)](#).
- [What is Epilepsy? - Epilepsy Action \(Video\)](#).
- [SUDEP & Seizure Safety for Carers of People with a Learning Disability or Autism - SUDEP Action \(Video\)](#).

Contact: If you have any queries about this newsletter or any of the topics raised here you can contact us on hnyicb-ny.mhld@nhs.net