

## North East and North Cumbria ICS Collaborative Annual LeDeR Report June 2022



This summary report is from the North East and North Cumbria Integrated Care System (ICS).






The information in the report covers the period 31<sup>st</sup> March 2021 – 30<sup>th</sup> June 2022.





It is a summary of key information from all NENC CCG Annual Reports.

## Contents





- Introduction
- About the Reviews
- Good Practice
- Learning Points
- Getting Ready to implement the new LeDeR policy in North East and North Cumbria
- Principles that underpin the work we do
- LeDeR Reports

## Introduction – written by the North East Stop People Dying Too Young Group

	<p>The LeDeR Programme has been going for 5 years now. Not enough change has happened in that time.</p>
	<p>People with a learning disability from Black, Asian and minority ethnic communities are dying younger than anyone else. This is not being talked about enough.</p>
	<p>The problems we face getting good health care have got worse during Covid.</p>
	<p>Services for people with a learning disability and autistic people will suffer when the NHS is stretched thin.</p>
	<p>People with a learning disability and autistic people are starting to be de-valued again.</p>

	<p>What does it cost to give us proper care?</p>
	<p>It is not just about the money. It is about respect and valuing us equally. That costs nothing.</p>
	<p>Our health problems need to be spotted early if we are going to stop people dying too young.</p>
	<p>More people need to have an Annual Health Check and they need to be face to face.</p>

	<p>There is still not enough information in Easy Read.</p>
	<p>And we need professionals to think about Easy Talk as well as Easy Read.</p>
	<p>We know that when our stays in hospital are planned in advance they can go really well. We need to know we will get just as good care in emergency situations.</p>
	<p>We need more support and information around the medication we are given.</p>

	<p>We need to understand the side effects and need more help to be independent with this.</p>
 <p>Training Room</p>	<p>We need professionals to know more about learning disability and autism. We hope that mandatory training will give this.</p>
	<p>How can we make sure that professionals have information about our individual needs? We know there are problems with hospital passports</p>
	<p>We think there should be more Learning Disability Liaison Nurses.</p>





Health services are still not involving people with a learning disability, autistic people and our families enough in making things better.


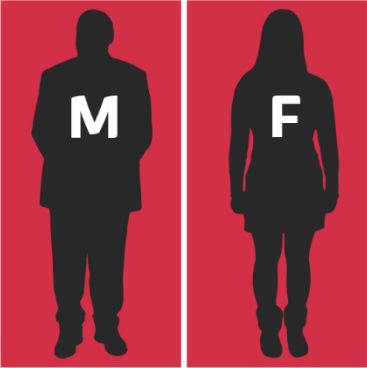



We are the experts on our lives.






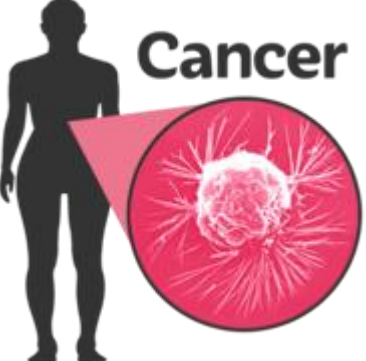

You need to hear from us what it is really like.  
Nothing about us without us.

## About the learning disability mortality reviews



	<p>This summary report looks at the deaths of 158 people with learning disabilities from the North East and North Cumbria Integrated Care System.</p> <p>In the North East and North Cumbria Integrated Care System there were 2 deaths of autistic people reported in February 2022. The findings from these reviews have not formally been shared as they have both been classed as sudden deaths and are awaiting a cause of death and may be subject to statutory processes.</p>
	<p>36% of the deaths were female and 64% were male.</p>
	<p>The majority of people were White British.</p> <p>We are unable to give exact figures of those from BAME communities (the LeDeR platform is not able to provide it).</p>






	<p>In future years we will want to provide this figure.</p>
	<p>65% of people died in a hospital setting.</p>
	<p><b>Pneumonia</b> - Infection in the lungs caused by germs was the leading cause of death in the North East and North Cumbria.</p> <p><b>Aspiration Pneumonia</b> - caused by food or drink going down the wrong way (into the lungs) was the second leading cause of death in the North East and North Cumbria.</p>
	<p>Problems related to the <b>heart</b> was the third most common cause of death in the North East and North Cumbria.</p>

 <p><b>Cancer</b></p>	<p><b>Cancer</b> was the fourth most common cause of death.</p> <p>The specific information about the types of cancer is not available.</p>
 <p><b>corona virus</b> COVID-19</p>	<p><b>Covid 19</b> continues to be a major concern for people with Learning Disability.</p> <p>The numbers of deaths from Covid 19 for people with learning disability compared to the rest of the population is almost double.</p> <p>This year there was a reduction in the number of people in North East and North Cumbria with learning disability, who died from Covid 19.</p>

## Good Practice

 <p>The illustration shows a woman in a wheelchair on the left, with a speech bubble above her that says "I need ...". To her right is a sign language interpreter. Further right is a clock and a sign that says "easy read" with some text and icons.</p>	<p><b>REASONABLE ADJUSTMENTS</b></p> <ul style="list-style-type: none"> <li>• Reasonable adjustments were recorded in GP records reflecting patient needs such as requiring home visits and flexible appointment times.</li> <li>• Communication and hearing needs were supported by a sign language interpreter.</li> <li>• Home visits were made by primary care team to support flu and COVID-19 vaccination.</li> <li>• Reasonable adjustments were clearly documented in GP records</li> <li>• GP practice had a named learning disability practice nurse to support communication and continuity of care.</li> </ul>
 <p>The illustration shows two women standing and talking. The woman on the left is wearing a black top and glasses. The woman on the right is wearing a pink top and is holding a blue folder or book.</p>	<p><b>COMMUNICATION</b></p> <ul style="list-style-type: none"> <li>• Clinical teams offered support to help families understand complex medical terminology and what this means for care and treatment.</li> <li>• Open communication between health and social care teams to support any additional support or care needs.</li> </ul>

	<p><b>DNACPR</b></p> <ul style="list-style-type: none"> <li>• Good understanding of Best Interest decisions.</li> <li>• Best Interests discussion recorded on Do Not Attempt CardioPulmonary Resuscitation (DNACPR)</li> <li>• High quality communication and decision making in relation to decisions about DNACPR to support emergency care planning.</li> </ul>
	<p><b>INVOLVING EVERYONE &amp; SHARED DECISION MAKING</b></p> <ul style="list-style-type: none"> <li>• Evidence of very good, coordinated care with excellent communication involvement of all services, MDT meeting shared decisions.</li> <li>• Evidence of effective Multi-disciplinary Team working.</li> <li>• Excellent support in the Community by a Multidisciplinary team.</li> </ul>
	<p><b>EASY READ RESOURCES</b></p> <ul style="list-style-type: none"> <li>• Learning disability service information leaflets are in easy read.</li> <li>• Easy read letters were sent to support appointments.</li> </ul>



## RECORD KEEPING

- Evidence of the implementation of the Mental Capacity Act and Best Interest Decision Making, inclusive of other professionals and the Next of kin
- Decision specific assessment of capacity evidenced in the record.



## HOSPITAL PASSPORTS

- My Health Record and/or hospital passport used and flag on record.



## ANNUAL HEALTH CHECKS

- Primary health care assessments and annual health care checks carried out in peoples own homes with carers or family present.



## PERSON CENTRED CARE

- Clinical staff supported parents to provide care at home at the request of the patient and their family.





## END OF LIFE PLANNING

- Evidence of Advance Care Planning Discussion for end of life care respecting patients wishes and preferences.
- All end of life care was implemented with compassion and care.



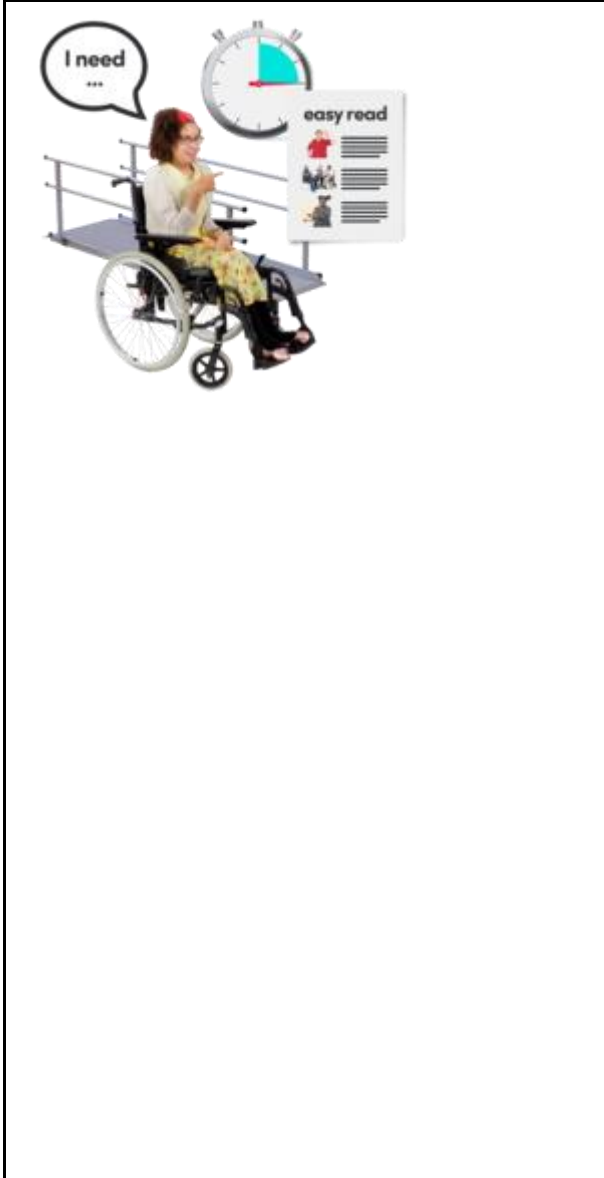
## Learning Points

	<p>People with learning disability are <b>continuing to experience long delays in having illness or disease diagnosed.</b></p> <p>This is largely due to the pandemic.</p> <p>We have created learning disability and autism population health management profiles for the ICB. The data is gathered from RAIDR and Waiting Well Data. The population health management data is being used at place and at ICB level to target inequality and long waiting times.</p>
 <p>GP Surgery</p>	<p>People with learning disability and autism <b>find telephone or video GP appointments very challenging.</b></p> <p>We have asked all GPs to revert to face to face appointments for people with learning disability and/or autism unless there is a clinical reason not to.</p> <p>Currently making learning disability and or autism diamond standards for primary care to improve quality and health outcomes. It will also include education for the workforce, incorporating the Oliver McGowan mandatory training.</p>



**Improved communication between health and social care.**

The pandemic provided opportunity to do things differently and removed communication barriers between health and social care. The ICB gives us further opportunity to build on this collaboration.



**Reasonable adjustments in place and clearly visible:**





The learning disability diamond standards for acute care are now fully implemented in every hospital across NENC.

All trusts are working towards 100% take up of workforce education and have implemented the care pathways.

The NEC Learning Disability Network website is being used as a central repository for tools best practice and resource to be shared across ICB.

[www.neclldnetwork.co.uk](http://www.neclldnetwork.co.uk)

All trusts have made improvements in flagging people with learning disability on hospital systems.

	<p>Whilst improvements are being made in the <b>quality of health action plans</b> this will be a major priority for 2022/2023 across the ICB.</p>
	<p><b>Staff training and awareness:</b> Acute hospitals are benefiting from roll out of diamond standards.</p> <p>The Be Screening Aware Teams (made up of experts with lived experience) have continued to deliver training to the health and social care workforce including fully revising the resource pack for social care for all 5 screening programmes.</p>
	<p><b>Improved sharing of care plans</b> across different systems</p>
	<p><b>Process for obtaining capacity/consent:</b> Learning Disability/autism Diamond Standards have supported improvements &amp; awareness of MCA and it continues to be a priority during 22/23 due to legislative changes</p>

## Getting ready to implement the new LeDeR Policy in the North east and North Cumbria

The steering group including the Confirm and Challenge groups and other important stakeholders have been working out how to make sure the North East and North Cumbria Integrated Care Board is able to deliver the new LeDeR policy.

LeDeR <https://leder.nhs.uk/>

LeDeR Easy Read Policy [LeDeR-Policy-2021-Easy-Read.pdf \(england.nhs.uk\)](#)

To do this we have completed work on:

- **Our Communication Strategy**

We have developed a 'Bulletin' so more people in the North East and North Cumbria to know about LeDeR.

The bulletin will provide any updates or changes to LeDeR such as important dates and changes to reporting a death.

It will be shared widely across health and social care systems and community and voluntary organisations on a bi-monthly basis.

This is how we will tell everyone what is happening in LeDeR.

Our communication strategy will make sure people with learning disability, autistic people and families

get to know about learning coming from mortality reviews and what is being done about it.

It will make sure the Integrated Care Board knows about learning coming from LeDeR, what is being done about it and that reviews are being completed within the timescales they should.

It will make sure health and social care providers across North East & North Cumbria know about learning coming from mortality review and what is being done about it.

- **Our Governance arrangements**

The LeDeR Steering group, that will become the Governance Board, is looking forward to welcoming David Purdue as North East and North Cumbria ICS Executive Director of Nursing with responsibility for LeDeR.

- **Our LeDeR learning into action workplan**

We will host an annual learning and sharing event. We will share examples of best practice across our region. We will ensure access to resources and training.

- **Our workforce requirements**

Across the North East and North Cumbria ICS there is a commitment that people with a learning disability, autistic people and family carers will be

involved as full and equal partners in all the work we do on LeDeR.

Our Confirm and Challenge Groups across the region have developed and designed a set of principles that will underpin all of the work we do:





# Our values for the Leder programme in the North East and North Cumbria



The lives of all people with a learning disability and autistic people have as much value as everyone else's.



We respect and value the lived experience that people with a learning disability, autistic people and family carers bring to this work.



People with a learning disability, autistic people and family carers will be involved as full and equal partners in all the work we do on Leder.



Everyone is unique, no matter what labels or diagnosis they have been given. We will not make any assumptions and we will treat everyone as an individual.

## LeDeR Reports

The [sixth annual Learning from lives and deaths – People with a learning disability and autistic people \(LeDeR\) report](#) has been published by King’s College London today, with [an easy read version](#).

NHS England has also published our [fourth annual LeDeR Action from Learning report](#) and [easy read version](#), which describes some of the work being undertaken across the country by the NHS to reduce health inequalities and premature mortality amongst people with a learning disability. There is also a [supporting resources document](#)

### North East and North Cumbria Reports

North Cumbria Annual Report:

[https://www.ncic.nhs.uk/download\\_file/view/8137/876](https://www.ncic.nhs.uk/download_file/view/8137/876)

North Tyneside Annual Report: <https://www.northtynesideccg.nhs.uk/wp-content/uploads/2022/07/NTCCG-Annual-LeDeR-Report-21-22.pdf?x68700>

South Tyneside/Sunderland Annual report: <https://nenc-southtyneside.icb.nhs.uk/news-media/publications/nhs-south-tyneside-ccg-nhs-sunderland-ccg-joint-leader-review-annual-reports/>

Durham: <https://nenc-countydurham.icb.nhs.uk/our-work/>

Tees Valley: <https://nenc-teesvalley.icb.nhs.uk/our-work/>

Northumberland Annual report:



2021 - 2022 LeDeR  
annual report -FINAL.c

The North East Stop People Dying Too Young Group made a film in response to the LeDeR National Annual Report 2021/2022 it can be found here:

<https://youtu.be/gZaB4ntXglQ>