

# North East & North Cumbria Integrated Care System

*LeDeR*

*Learning from Life and Death Reviews*

*Revised Governance Arrangements,  
Implementation Plan and 3 Year Strategic Plan*

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## Background and context

LeDeR; Learning from Life and Death Reviews is a service improvement programme to improve services for people with a learning disability and autistic people.

Responsibility for ensuring the delivery of LeDeR currently (2021/22) lies with CCGs and as the systems evolve over the next year, responsibility and accountability for LeDeR will change to rest with Integrated Care Systems (ICS). North East and North Cumbria (NENC) is already working together as one ICS and will become a statutory organisation, subject to approvals by Parliament, from 1 April 2022. NCNE ICS have named Learning Disability and Autism as one of their six priority workstreams under the leadership of Nicola Bailey who is currently Accountable Officer at County Durham CCG.

This report provides the LeDeR draft implementation plan and new governance arrangements required to be in place by 1 April 2022.



- A full version of the new policy can be found [here](#).
- An easy read version of the policy can be found [here](#).
- Find out more about the North East & North Cumbria Integrated Care System [here](#).

## Local delivery expectations

NENC have a history of meaningful engagement and coproduction with people with lived experience and established the Stop People with Learning Disability Dying Too Soon Confirm and Challenge Group. Feedback from the Group about being part of the future Governance arrangements is as follows:

*'We felt very respected being at the heart of the plans'*

*'We love the jobs in the area teams for Experts'*

*'We feel like it brings people together to all work together'*

*'It focuses on making changes to make things better'*

The NENC ICS has already made some progress in relation to the delivery expectations of the new LeDeR policy including having a named lead for Black, Asian and Minority Ethnic Inequalities. Annie Topping is Executive Director of Nursing, Quality and Patient Safety at Northumberland CCG. NENC also demonstrated its commitment to narrowing the gap in health inequalities and premature mortality during (2020/21) when 74% of people on the learning disability register received an annual health check.

At present there are robust plans in place within CCGs to ensure that reviews are completed within 6 months of notification of death. It is anticipated that delivery of reviews will remain at 'place'.

Reviewers at Place will systematically capture evidence where recommendations are being made, that they are being acted upon or that changes are having the desired impact. Through the Local Area Contacts (LAC), reviewers will feed into the Steering Group any action from learning required and any areas for escalation. The NENC Learning Disability Network will continue to be the mechanism for using the learning from Leder reviews to improve services.

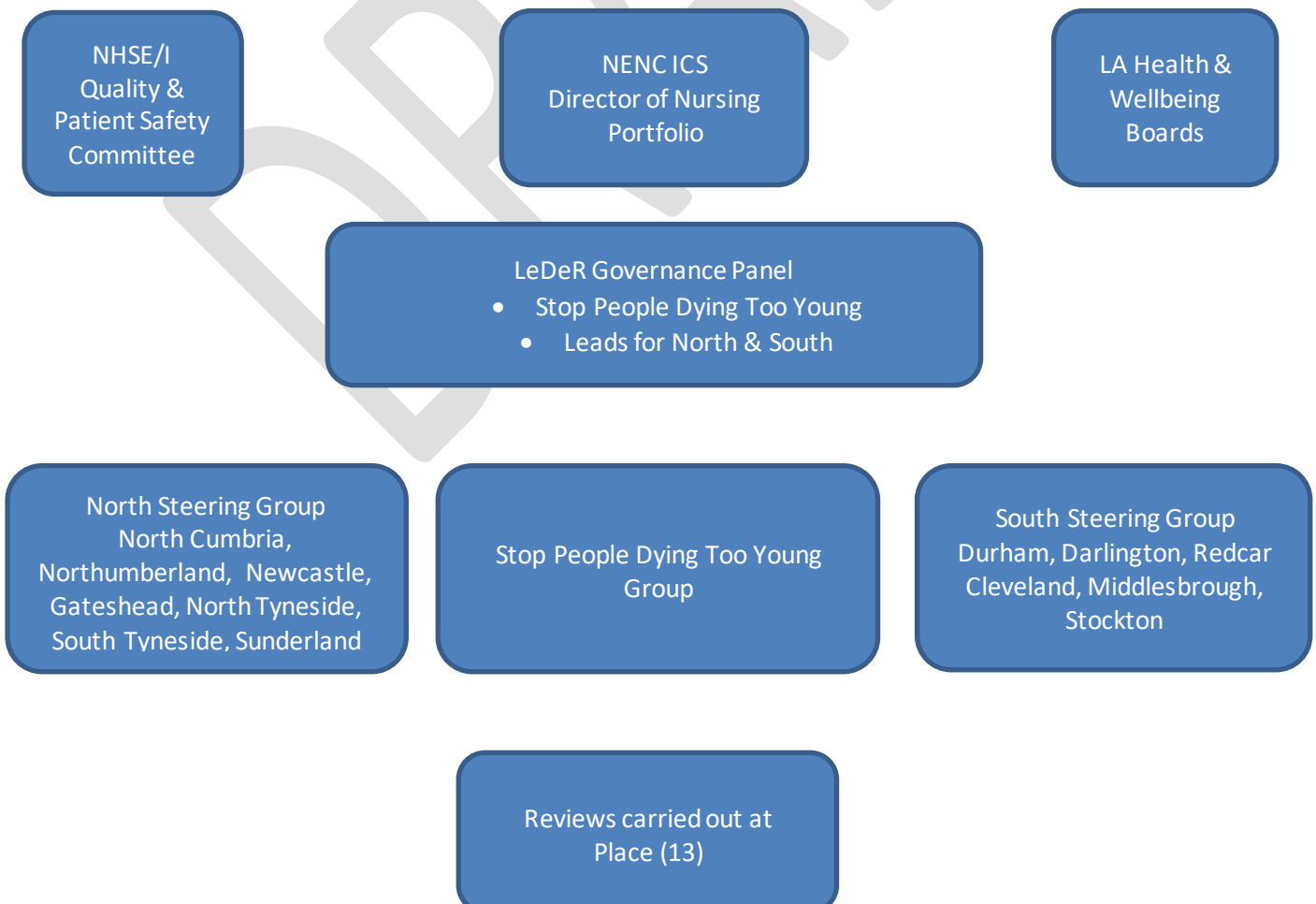
## Governance and Assurance

It is the responsibility of individual ICSs to determine how LeDeR is best governed within its own quality and governance arrangements, Regional oversight arrangements will include NHSE/I sampling to assure quality of reviews.

Local governance arrangements will feed into local Quality Surveillance Groups and, for Local Authorities, Health and Wellbeing Boards, to ensure that the people who can affect the necessary improvements understand the issues that need to be addressed.

ICSs will become responsible for ensuring:

- that LeDeR reviews are completed for their local area
- that actions are implemented to improve the quality of all mainstream services for people with a learning disability to reduce health inequalities and premature mortality.
- that local actions are taken to address the issues identified in reviews.
- that recurrent themes and significant issues are identified and addressed at a more systematic level.



## **The ICS Governance Panel membership will include representation from:**

- Stop People with Learning Disability Dying Too Young Confirm & Challenge Group
- ICS senior leaders
- The Learning Disability Network
- NHS England
- Local Area Contacts leads from the North and South
- Local Authorities
- Acute Hospitals
- Specialist Learning Disability Hospitals
- Primary Care Networks
- Coroner's Office
- Care Quality Commission

### **The Role of the ICS Governance Panel:**

- signing off the quality of focused reviews
- oversight on quality of reviews
- areas of learning
- good practice
- areas of concern
- feed into strategic plan for NENC
- Inc people with lived experience
- NHSE/I Quality surveillance
- ICS quality governance

## Workforce Planning

The role(s) expected of the LAC will sit within the ICS. This is a different role to the current LAC role and there will be greater independence between the reviewing team and the LAC in future. The LAC(s) will chair the Governance Panel and be responsible for reporting into NHSE/I, the ICS and LAs through the agreed mechanisms (see Governance diagram above).

The Senior Reviewer is a new role which will lead a multidisciplinary team of reviewers providing professional and line management support and professional/clinical supervision and ensuring that the team works cooperatively together to deliver all the reviews within their remit. The Senior Reviewer(s) will chair the North and South Steering Groups and be responsible for reporting into the LeDeR Governance Panel.

Reviewers will work in teams (one North and one South) to allow peer support and to ensure improved quality and consistency. Reviewers should be using NHS or LA IT equipment that is compliant with Information Governance rules.

The revised workforce model will also need to include time to gather and present the learning and recommendations that come from reviews at the various forums as described in the Governance Diagram.

Dedicated Business Support will be employed as part of the ICS Workforce Model to support the ICS Governance Panel, the North and South Review Teams and to provide support to the ICS LeDeR review process generally. The Business Support Role will coordinate production of the ICS LeDeR Annual Report as well as preparation of reports into NHSE/I Quality and Patient Safety Committee and Local Authority Health and Wellbeing Boards. The business support role will also lead on performance reporting which is critical to ensure that NENC is aware of its ability to reach the KPIs and can take appropriate action to address any under/over resourcing.

Autistic people die on average 16 years younger than the general population and in 2021, the LeDeR process will include the deaths of autistic people.

[Personal-tragedies-public-crisis-ONLINE.pdf \(autistica.org.uk\)](https://www.autistica.org.uk/personal-tragedies-public-crisis-ONLINE.pdf)

Since we have yet to begin reviewing the deaths of autistic people, it is difficult to predict the demand and the associated workforce resource required and this remains an estimate.



## Calculating the number of reviews – assumptions used

The following workforce model is based on a number of assumptions in the total number of reviews which can be tested and revised during October 2021 to March 2022, including:

- 6.52% of the NENC population is from Black, Asian and Minority Ethnic groups
- 2.16% of the NENC population has a learning disability (they may also be autistic)
- 1% of the NENC population is autistic
- The baseline used for notifications is 20-21 and the estimated conversation rate on these reviews is 50%
- 0.01% of families/carers etc will request a review; these will be additional to the baseline notifications and there will be a 50% conversion rate from initial to focussed reviews
- There will be half as many deaths of autistic people reported through the LeDeR platform as learning disabled people

More detail can be found in Appendix 2.

## Workforce Modelling

<b>NENC LeDeR Workforce Model</b>			
<b>Time to complete reviews</b>		<b>Initial</b>	<b>Focussed</b>
Hours to complete reviews (ref NECS modelling)		12	45
Number of reviews		154	243
Hours to complete reviews		4764	10935
Total time needed (hours)			15699
<b>Workforce needed to complete reviews</b>			
Reviewer FT 220 days per year	1650		
Reviewers needed	9.5		
Reviewer - learning into action	1		
Total reviewers needed B7	10.5		
LAC B8c	0.2		
Senior Reviewer B8a 2 x 0.5	1		
Project Support B6	0.5		
<b>Costs based on 20-21</b>			
	<b>WTEs</b>		<b>£</b>
Total reviewers needed B7	10.51		614,846
LAC B8c	0.2		19,539
Senior Reviewer B8a	1		68,131
Project Support B6	0.5		24,867
Total cost to ICS			<b>727,382</b>



## Risks and Mitigation

There are a number of risks in transition to new LeDeR workforce model:

- Future ICS governance arrangements have not been confirmed, this model assumes that LeDeR will be within the Director of Nursing Portfolio who will sit on the ICS Board
- CCG reviewers are currently working at place and will be required to transition to one ICS, in addition there are few WTEs who are solely employed to carry out LeDeR reviews; this results in the inability to accurately measure time spent to date on reviews and therefore to accurately monitor/predict exact resource required; this risk can be mitigated through the consideration of a blended delivery model with North of England Commissioning Support Unit partners
- Monitoring and reporting needs to be set up to ensure that the ICS is meeting the KPIs; systems and processes will need to be established by April 2022
- Deaths of autistic people will not be able to be notified to the system until later in 2021 there for it is difficult to plan effectively
- The workforce model assumes that the ICS will continue to receive the annual LeDeR funding from NSHE/I.



## Implementation Plan and 3 Year Strategic Planning; Key areas for Improvement; Themes and Priorities

CCGs across NENC ICS have completed their Local Area LeDeR Annual Reports for deaths reported 1<sup>st</sup> April 2020 – 31<sup>st</sup> March 2021. The reports offer opportunities to highlight areas of best practice, note where improvements are required and share the learning and recommendations from LeDeR reviews. The information contained in these reports will influence the strategic priorities of the NENC ICS Learning Disability and Autism Workstream and directly impact the implementation of the new LeDeR policy for the region. The following plan should be viewed as the first draft and will be a live document owned by the LeDeR Governance Panel and LeDeR Steering Groups.

Development Area	Objective	Progress to date	Timeline for completion
1. Governance	Have a named lead with responsibility for Black, Minority Ethnic inequalities	In place; Annie Topping Executive Director of Nursing, Quality and Patient Safety, NHS Northumberland CCG and NHSE/I (North East and Yorkshire) Strategic Lead for Chief Nursing Officer (England) BAME SAG Action Plan	Complete
	Identify a named executive lead as SRO for LeDeR within the ICS	Nicola Bailey is SRO for the Learning Disability and Autism Workstream	Complete
	A robust plan in place to ensure that reviews are completed within 6 months of the notification of death	NCNE completed 100% of cases within the 6 month KPI prior to the new operating system. Future workforce plan in development.	See Workforce Plan
	Evidence of meaningful engagement of people with lived experience in governance group	The Stop People Dying too Young Confirm and Challenge Group are part of the current and future governance arrangements and produce a Newsletter which is disseminated.	Draft Plan in place by 30th September 2021 Delivery from April 2022

	<p>Quarterly report demonstrating progress against delivery of LeDeR actions RAG rated</p>	<p>Monthly progress reports into Executive Strategy Group; broken down by CCG, provides opportunity to escalate via CCG Accountable Officers (and ICS equivalent once confirmed). Quarterly reports will be accompanied by a Newsletter for Acute Trusts, LA Commissioners and ADASS colleagues. The ICS Website will also be a repository for LeDeR information.</p>	<p>Draft Plan in place by 30th September 2021 Delivery from April 2022</p>
	<p>Clear Governance in place which includes LeDeR governance in mainstream ICS quality surveillance and governance arrangements</p>	<p>Development of process for reporting areas of concern and sharing learning/action from learning required via regional Quality Surveillance Groups. See Governance diagram</p> <p>NCNE will work with the ICSs in Y&amp;H to provide a quarterly report to the NEY Quality and Patient Safety Committee to highlight any learning.</p> <p>Escalation process will be via the NCNE Executive Strategy Group and the LACs in the first instance.</p>	<p>Draft Plan in place by 30th September 2021 Delivery from April 2022</p>
	<p>Development of 3 year strategy shared with NHSE/I's Regional Team</p>	<p>See below</p>	<p>Draft Plan in place by 30th September 2021</p>
	<p>Sustainable workforce model in place</p>	<p>See Workforce Planning</p>	<p>Draft Plan in place by 30th September 2021 Delivery from April 2022</p>
	<p>Local Governance Panel in place</p>	<p>See Governance and Assurance</p>	<p>Draft Plan in place by 30th September 2021 Delivery from April 2022</p>

**3 Year Strategic Plan to deliver a reduction in the gap in health inequalities and premature mortality**

<p>2. Reducing Health inequalities</p>	<p>To drive improvement in the quality of health and social care service delivery for people with learning disabilities</p>	<p>The current LeDeR work programme is directly linked to the broader tackling health inequalities work programme of the North East and Cumbria Learning Disability Network. The priorities which have been set for 2021/24 are:</p> <ul style="list-style-type: none"> <li>Pneumonia</li> <li>Aspiration pneumonia</li> <li>Cancer</li> <li>Wider health promotion</li> <li>End of life</li> <li>Flagging</li> <li>Sepsis</li> <li>Constipation</li> <li>Epilepsy</li> <li>Mental Capacity Act</li> <li>AAA Screening Programme</li> <li>Dementia</li> <li>Oral care</li> <li>NHS 111 and Urgent Care</li> </ul> <p>Data dashboard in development with NECS will provide live monitoring information on Primary Care Registers to enable targeted approaches based on that data.</p>	<p>NB each one of the areas has its own activity, action plan and timeline managed through and by the Learning Disability Network which would provide too greater detail for the Strategic Plan.</p> <p>Ongoing with review against baseline at April 2022</p>
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<p>3. Annual Health Checks</p>	<p>Improve how the Annual Health Checks and Health Action Plans work. This will include:          Use of Easy Read for more effective AHCs          A training support programme for staff          Updates to Health Action Plans to show support for healthy lifestyle</p> <hr/> <p>Continue to raise awareness across the ICS of the importance of the AHC, including with families and carers and PCNs.</p> <hr/> <p>Respond to performance rates of AHC to provide support to the ICS to ensure the national target is met year on year</p>	<p>Good Access to Primary Care Services Network (GAPS)          The North East and Cumbria GAPS Network is a regional network made up of the learning disability primary care facilitators from across the region. The network is facilitated and supported by the North East and Cumbria Learning Disability Network.          The GAPS network has been established since 2018 and has led on a range of initiatives to improve the care and experiences of people with a learning disability in primary care services. The network meets 6 weekly with their current 2021 focus on:</p> <ul style="list-style-type: none"> <li>• Facilitating reasonable adjustments in general practice and primary care</li> <li>• Improving the quality and uptake of learning disability Annual Health Checks</li> <li>• Improving GP learning disability registers</li> <li>• Provide learning disability awareness training to GP Practices</li> <li>• Improving access, health and health outcomes and experiences of primary care service for people with a learning disability and their families reducing premature mortality</li> <li>• Peer review</li> <li>• Covid19 vaccination roll out</li> <li>• Improving uptake of flu immunisation in people with a learning</li> </ul>	<p>Ongoing with review against baseline at April 2022</p>
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	<p>Review AHC resources and coproduce for autistic people in line with national roll out of AHCs</p>	<p>disability and their carers</p> <ul style="list-style-type: none"> <li>• Development and implementation of the Learning Disability Diamond Standard Primary Care Pathways and Workforce Education Package</li> <li>• Working in partnership with the A2A and Learning Disability CCG Clinical Leads networks.</li> </ul> <p>During the Covid19 pandemic the North East and Cumbria Learning Disability Network will continue to support our network members to improve the uptake and quality of Annual Health Checks through:</p> <ul style="list-style-type: none"> <li>• Learning disability Annual Health Check pre-questionnaire</li> <li>• Annual Health Check risk stratification tool to support GP practices whilst managing the pandemic</li> <li>• Primary care resource pack for GP practices</li> <li>• Support General Practice and CCGs to design and deliver 'reasonably adjusted' Annual Health Check models</li> <li>• Resources:</li> </ul> <p><a href="https://www.youtube.com/watch?v=e3ZSPDyBAVA&amp;t=27s">https://www.youtube.com/watch?v=e3ZSPDyBAVA&amp;t=27s</a></p> <p><a href="https://neclidnetwork.co.uk/wp-content/uploads/2021/01/What-is-AHC-Flu-Registers.docx">https://neclidnetwork.co.uk/wp-content/uploads/2021/01/What-is-AHC-Flu-Registers.docx</a></p> <p>Current work focusing on AHCs for children and young people, awareness and access to AHCs with aim of developing sustainable health behaviours and access to primary care. Funding application in with national team to develop resources specifically for this age group.</p>	
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<p>4. Reasonable Adjustments</p>	<p>Raising awareness of Reasonable Adjustments within all action areas. For example:</p> <p>Providing Easy Read leaflets/resources</p> <p>Longer appointments</p> <p>Helping people with their choices and how they can have reasonable adjustments made</p>	<p>Learning Disability Acute Diamond Pathways</p> <p>In 2020 The Learning Disability Diamond Standards have been developed by the North East and Cumbria Learning Disability Network and Access to Acute (A2A) Network to support NHS Acute Trusts to deliver high quality, reasonably adjusted care to people with learning disability.</p> <p>Resources:</p> <p>A4_Learning_Pack.pdf (neclnetwork.co.uk)</p> <p>PowerPoint Presentation (neclnetwork.co.uk)</p> <p>Currently developing diamond pathways for primary care with support from Clinical leads network and GAPs network.</p>	<p>Ongoing with review against baseline at April 2022</p>
<p>5. Screening programmes</p>	<p>Supporting people to take part in screening programmes</p>	<p>Long established cancer project with focus on screening, resources available at: <a href="https://neclnetwork.co.uk/work-programmes/health-inequalities/cancer/cancer-screening/">https://neclnetwork.co.uk/work-programmes/health-inequalities/cancer/cancer-screening/</a></p> <p>Currently developing new peer education programme Be Screening Aware in partnership with National PHE screening team and Northern Cancer Alliance.</p> <p>Work in partnership with Screening and immunisation team and local screening centres.</p> <p>Currently piloting health quality checks in breast and bowel screening in partnership with Skills for People and Sunderland People First.</p>	<p>Ongoing with review against baseline at April 2022</p>



<p>6. Hospital passport</p>	<p>Increase use of across Secondary Care</p>	<p>Every Acute Trust in our region offers a paper Hospital Passport to people with a learning disability. Through the Covid19 pandemic we have developed a regional Covid19 Hospital Passport which can be accessed here: <a href="https://neclnetwork.co.uk/wp-content/uploads/2021/01/Word-Hospital-Passport.pdf">https://neclnetwork.co.uk/wp-content/uploads/2021/01/Word-Hospital-Passport.pdf</a></p> <p>Current project developing/creating a digital hospital passport which will standardize hospital passport for the whole region. Supported by Health call, Great North Care Record and Skills for People.</p>	<p>Ongoing with review against baseline at April 2022</p>
<p>7. Workforce, Training, Information and Awareness</p>	<p>Making sure professionals have safeguarding and equality training</p>	<p>The Acute diamond standards include an e-learning and face to face delivery resource. This has been adopted by all trusts across the ICS. To be a diamond standard ward/organisation 70% of staff need to have completed the training.</p> <p>Due to a lack of guidance about how best to support people with learning disability to learn about the PBS approach and no nationally-agreed standards about the training requirements or qualifications and experience individuals or services need to have, the North East and Cumbria PBS Steering Group worked collaboratively with a number of partners from across the health and care sector and with Northumbria University to co-develop, validate, co-deliver and evaluate a range of accredited learning programmes in Positive Behavioural Support for the North East and North Cumbria.</p>	<p>Ongoing with review against baseline at April 2022</p>
	<p>Sharing information on early warnings of illness</p>	<p>As such, the PBS approach is becoming a way of life across health, social and education care in the North East and North</p>	

	<p>More training for hospital staff around Learning Disabilities and the Mental Capacity Act</p>	<p>Cumbria.</p> <p>The North East and North Cumbria PBS work programme has its own website which was launched in January 2021 and can be found here <a href="http://www.pbsnec.co.uk">www.pbsnec.co.uk</a></p> <p>Early warning resources</p> <ul style="list-style-type: none"> <li>• Developed resources include Stop and Watch.</li> <li>• Ongoing commitment to Confirm and Challenge group – Inclusion North</li> <li>• Continued promotion of AHC/Health Action Plans</li> <li>• Promotion of covid vaccination and flu vaccination</li> <li>• Work with Northern Cancer Alliance on awareness campaigns Be Cancer Aware « Learning Disability Network (<a href="http://neclidnetwork.co.uk">neclidnetwork.co.uk</a>)</li> </ul> <p>Workforce</p> <p>Our collective vision is that the North East and Cumbria will be the best place in England for a person with learning disability and/or autism and their family to live. In a rapidly-changing political, economic and social environment it is of paramount importance to have a robust workforce transformation and delivery plan in place to support the multi-disciplinary workforce and family carers</p> <p>We are doing this by transforming the workforce to support people to live better, more fulfilling lives and to enable better care and support to be delivered closer to home, with earlier and more appropriate intervention when necessary.</p> <p>The updated NCNE Learning Disability and Autism Workforce Strategy is in draft with the Workforce Plan to follow in early 2022.</p>	
<p>8. Choice and control</p>	<p>Comprehensive End of Life Planning</p>	<p>To improve recognition of people (and their families) who are nearing the end of their lives, to develop education and training materials and increase awareness of appropriate responses across health and social care.</p> <p>Currently working with Palliative care and End of Life Network to</p>	<p>Ongoing with review against baseline at April 2022</p>

		develop easy read resources in partnership with experts by experience from Inclusion North.	
	Improved completion of assessments and forms inc. <ul style="list-style-type: none"> <li>• Medication reviews</li> <li>• Discharge information</li> </ul>	STOMP and STAMP project - to promote alternatives to medication. Dave Gerard and Ruth Lee – PBS Workforce Development Manager leading discussions on project.	
	How to work with people if they say no to treatment/ Follow up on missed appointments/no show	Current work looking at 'Adult not brought' flagging and processes led by clinical leads network with partners from across primary and acute services.	
9.Communication	Improved communication between health, social care and families	<p>Appointment of Workforce Development Manager for Families</p> <p>PBS website aims to:</p> <p>Have a shared vision that brings families and professionals together with the aim to improve the quality of life of children, young people and adults with a learning disability and or autism.</p> <p>Have a shared understanding that PBS can be hugely effective in helping a group of people to best understand a person with a learning disability and or autism to support them to have the best life possible</p> <p>Share resources the website is a platform to reach out to families, carers and services sharing useful and practical information as well as celebrating the quality of PBS work in the North East and North Cumbria and the lives of people with a learning disability</p> <ul style="list-style-type: none"> <li>• Primary care bulletin</li> <li>• NECLDnetwork.co.uk website</li> <li>• Learning disability matters to families website</li> </ul>	Ongoing with review against baseline at April 2022

## Appendix 1 LeDeR Policy Changes - Easy Read



NENC LeDeR model  
v2 ER.pdf

## Appendix 2

<b>Estimating the total number of Leder Review over a twelve month period</b>			
	<u>Total Population in NENC</u>		3315740
	BAME Population	6.52%	216340
	% BAME and learning disability (est)	2.16%	4673
	% BAME who are autistic (est)	1%	2163
	% of popn with a Learning disability	2.16%	71620
	% of popn who are autistic	1%	33157
	Notifications 20-21		298
	as a % of popn:- people with a learning disability	0.42%	
	<u>Estimated additional reviews</u>		
Initial	Requested by families (est)	0.01%	5
Focussed	Requested by families (est)	0.01%	5
Focussed	Autistic people (including BAME popn)	0.21%	70
Focussed	BAME who have a learning disability and are autistic	0.42%	20
	<u>Notifications 20-21 est 50% conversation rate</u>		
Initial			149
Focussed			149
	<u>Total initial reviews</u>		154
	<u>Total focussed reviews</u>		243