North East & Cumbria Learning Disability Network

Reducing Premature Mortality in People with Learning Disabilities
LeDeR Learning & Sharing Event

19th July 2016
Learning Disability Mortality Review
North East and Cumbria Pilot

Dr Dominic Slowie
National Clinical Director for Learning Disability
18th July 2016
The Ultimate Health Inequality

- 58 times more likely to die before the age of 50
- Three times more likely to die from something that good care could have stopped
- 25 deaths a week could be stopped
LeDeR: My First Priority

Make improvements to the lives of people with learning disabilities

Wayne  Charlotte  Gemma
BUILDING THE NHS OF THE FIVE YEAR FORWARD VIEW

Martin’s story

“Martin was often smiling – he loved to go out, liked the movement of the coach and listening to the music. When he was young, he liked being in our car as well. He loved getting behind the wheel and turning it around.”

Martin died on 21 December 2005, aged 43 years old, allegedly of a stroke. He had a severe learning disability and no speech. In the 26 days he spent in hospital following a stroke he went without food.
Data on Health Inequality

- Total Population with a BMI over 30:
  - Yes: 9.3%
  - No: 90.7%

- Total Learning Disability Population with a BMI over 30:
  - Yes: 21.4%
  - No: 78.6%
South Tees female LD patients with no hysterectomy who have had Cervical screening in the last 3yrs if aged 25-49/5yrs if aged 50-64yrs old

South Tees LD Cervical screening rate was also 28% in 2014-15
(500/139=28%)

Screening seems to decrease with severity and Declined/Excepted seems to rise

<table>
<thead>
<tr>
<th>Severity</th>
<th>Screened*</th>
<th>Declined*</th>
<th>Remaining</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>35.16%</td>
<td>31.25%</td>
<td>33.59%</td>
<td>128</td>
</tr>
<tr>
<td>Moderate</td>
<td>25.26%</td>
<td>40.00%</td>
<td>34.74%</td>
<td>95</td>
</tr>
<tr>
<td>Severe</td>
<td>9.26%</td>
<td>50.00%</td>
<td>40.74%</td>
<td>54</td>
</tr>
<tr>
<td>Profound</td>
<td>0.00%</td>
<td>80.00%</td>
<td>20.00%</td>
<td>5</td>
</tr>
<tr>
<td>No severity</td>
<td>30.54%</td>
<td>43.84%</td>
<td>25.62%</td>
<td>203</td>
</tr>
</tbody>
</table>

*Screening/Declined in the last 3/5 years respectively, Declined includes no response and excepted, Remaining are those patients still eligible

South Tees Cervical Screening programme had an uptake of 74% in 2014-15

Source(s): Cancer Research UK / Health and Social Care Information Centre and Open Exeter. (2016) (screening based on the last 3.5/5.5 years not 3/5 years.)
Annual Health Checks
Flu Immunisation
Others want to help…. 

1. Do you have anyone with a learning disability in hospital at present?
2. What reasonable adjustments do you make for people with learning disability?
3. Do you have a specialist nurse for learning disability?
4. Do you audit the care given to patients with learning disability?
Acute Liaison Nurses
Historical Contexts
Safer Down's test backed for NHS use  BBC News January 2016
BRS.....and the New Model

9 Principles

1. Meaningful Life
2. Person centred proactive care
3. Choice and Control
4. Carers are supported
5. Choice about where and who I live with
6. Mainstream services work too
7. Specialist support…In the Community
8. Preventative support
9. In ATU high quality, short time
Good jobs make us healthy
Having your own home makes you healthy
Being with Family and Friends makes us healthy
Two Boxes Can Keep People Alive
- Health is as important as healthcare
- There is no health without independence and well being
- What do 2 boxes look like in my world?
- An improving learning disability mortality picture is an improving picture of health?
Thank you

dominic.slowie@nhs.net

@dominicslowie
National Context
Learning Disabilities Mortality Review (LeDeR) Programme

Robert Tunmore
Robina Mallett
Key Programme aims

• To drive improvement in the quality of health and social care service delivery for people with learning disabilities.

• To help reduce premature mortality and health inequalities in this population.
Two key elements of the Programme

• To support local areas to conduct reviews of deaths of people with learning disabilities

• Series of additional projects
Reviews of deaths

All deaths of people with a learning disability aged between 4-74 years.

Deaths of children aged 4-17
Reviewed by Child Death Overview Process. Local reviewer liaises with team to offer learning disability expertise if appropriate and ensure collection of core data for LeDeR Programme.

Deaths subject to Priority Themed Review
A subset of anonymised reports of deaths to be reviewed externally. All will have been to multiagency review. In Year 1 this will be deaths of young people aged 18-24, or from Black and Minority Ethnic Communities.
## Local context – Standardised Mortality rates

<table>
<thead>
<tr>
<th>(Former) Strategic Health Authority Area</th>
<th>Age standardised mortality rate (CI) for people with learning disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>West Midlands</td>
<td>3.59 (2.86 - 4.50)</td>
</tr>
<tr>
<td>South West</td>
<td>3.26 (2.72 – 3.92)</td>
</tr>
<tr>
<td>North West</td>
<td>3.11 (2.60 – 3.73)</td>
</tr>
<tr>
<td>North East</td>
<td>3.09 (2.05 – 4.64)</td>
</tr>
<tr>
<td>East of England</td>
<td>2.97 (2.30 – 3.85)</td>
</tr>
<tr>
<td>London</td>
<td>2.89 (2.35 – 3.56)</td>
</tr>
<tr>
<td>East Midlands</td>
<td>2.30 (1.15 – 4.59)</td>
</tr>
<tr>
<td>South East Coast*</td>
<td>Data is not robust</td>
</tr>
<tr>
<td>Yorkshire and the Humber*</td>
<td>Data is not robust</td>
</tr>
</tbody>
</table>
Expected numbers of deaths of people with learning disabilities each year

<table>
<thead>
<tr>
<th></th>
<th>Age 0-17</th>
<th>Age 18-74</th>
<th>All ages</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>78</td>
<td>2,209</td>
<td>2,976</td>
</tr>
</tbody>
</table>

These are estimates of people with learning disabilities identified on GP registers.

On average, in England, we estimate that half as many people with learning disabilities die each year than children aged 0-17.
Local reviews of deaths

Purpose:
To help health and social care professionals and policy makers to

• Identify the potentially avoidable contributory factors related to deaths of people with learning disabilities.

• Identify variation and best practice in preventing premature mortality of people with learning disabilities.

• Develop action plans to make any necessary changes to health and social care service delivery for people with learning disabilities.
Process of local reviews of deaths

Notifications
LeDeR Team receive notification.

Inform and assign case
- LeDeR team informs Local Area Contact (LAC) of a new case.
- LAC agrees allocation with Reviewer.
- LeDeR informs Reviewer of the case allocation.

Initial Review
- Reviewer conducts the initial review within 4 weeks.
  - Review of relevant case notes.
  - Conversation with someone who knew the person well (family members or other key people).
  - Complete pen portrait, timeline and action plan.

Further Action: Prepare for Multi Agency Review
- Contact other agencies involved.
- Contact family members.
- Request relevant notes and documents.
- Arrange and prepare for multi-agency review meeting.
- Update case documentation.

Multi Agency Review Meeting
- Agree pen portrait and timeline.
- Agree potentially avoidable contributory factors.
- Identify lessons learned.
- Agree on good practice and any recommendations.
- Complete Action Plan.

Summary and Close
The completed report and action plan is returned to the LAC for sign off and the LeDeR Programme.

Decide whether further action is required
- Further action is required if:
  - Additional learning could come from a fuller review.
  - If it is a Priority Themed Review.
  - If red flags indicate this.

No Further Action
The completed report and action plan is returned to the LAC for sign off and the LeDeR Programme.

Local Action
- LAC shares anonymised learning points and actions with the Local Area Steering Group to ensure learning is embedded.
- Action plans are taken forward.

LeDeR Programme

Priority Themed Reviews

Reviews

LeDeR Programme

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LeDeR Programme
Operational delivery of local reviews of deaths

**Steering Group** in each NHS England Local Area to take strategic level oversight of the reviews of deaths of people with learning disabilities in that area.

Multiagency representation, including: primary and secondary healthcare, social services, public health, voluntary sector, family representatives etc.

- To guide the implementation of the programme of local reviews of deaths.
- Liaise with Local Area Contacts / support LeDeR Reviewers
- Monitor action plans resulting from reviews and take appropriate action.
Family Carer Involvement

LeDeR’s objective ‘*To put people with learning disabilities and their families at the centre of the development and delivery of the work programme*’. 
What does ADASS think of the Programme?
## What is ADASS?

<table>
<thead>
<tr>
<th>Image</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Map of UK" /></td>
<td>ADASS is a national organization of senior managers in local councils who run adult social care services</td>
</tr>
<tr>
<td><img src="image2.png" alt="Bosses" /></td>
<td>Bosses of Adult Social Care are called Directors</td>
</tr>
<tr>
<td><img src="image3.png" alt="Person" /></td>
<td>People with learning disabilities have the same rights as every one else</td>
</tr>
</tbody>
</table>
Choice and Control

We want to help make services better, so that people with learning disabilities:

<table>
<thead>
<tr>
<th>Live where they want</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have a good life, with good health</td>
</tr>
<tr>
<td>But sometimes people do not have this.... Sometimes they die.</td>
</tr>
</tbody>
</table>
It’s very sad.

Sometimes it’s a surprise.

This could be because:

<table>
<thead>
<tr>
<th>Image</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Image" /></td>
<td>A person is ill and nobody realized how bad it was</td>
</tr>
<tr>
<td><img src="image2.png" alt="Image" /></td>
<td>A person is treated badly or neglected and this causes them to die</td>
</tr>
<tr>
<td><img src="image3.png" alt="Image" /></td>
<td>There is an accident, and the person do not survive</td>
</tr>
</tbody>
</table>
There must be a review

<table>
<thead>
<tr>
<th></th>
<th>ADASS think it’s essential to look into unexpected deaths for everyone.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>What’s the truth about what happened?</td>
</tr>
<tr>
<td></td>
<td>What can we learn?</td>
</tr>
<tr>
<td></td>
<td>What can we do to stop this happening?</td>
</tr>
</tbody>
</table>
What makes it difficult to do?

<table>
<thead>
<tr>
<th>Image</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Know Your Rights" /></td>
<td>Some people don’t know about rights</td>
</tr>
<tr>
<td><img src="image2.png" alt="People Reading" /></td>
<td>People don’t know which process to follow (Police, Safeguarding, Incident investigation)</td>
</tr>
<tr>
<td><img src="image3.png" alt="Data Protection Act" /></td>
<td>People don’t think they can share personal information</td>
</tr>
<tr>
<td><img src="image4.png" alt="Person Frowning" /></td>
<td>People are frightened to tell the truth</td>
</tr>
<tr>
<td><img src="image5.png" alt="Nurse Writing" /></td>
<td>Information may not have been recorded properly. There may be no evidence.</td>
</tr>
</tbody>
</table>
### What do we think will help?

<table>
<thead>
<tr>
<th>Make sure people know when and where to report deaths of people with learning disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make sure people know about the law - Safeguarding Adults,</td>
</tr>
<tr>
<td>Agree to share information, properly.</td>
</tr>
<tr>
<td>Train people to look at evidence and write good reports.</td>
</tr>
<tr>
<td><strong>Care Act 2014, S44</strong></td>
</tr>
<tr>
<td>------------------------</td>
</tr>
<tr>
<td>When someone with care and support needs has died</td>
</tr>
<tr>
<td>It is suspected the death resulted from abuse or neglect</td>
</tr>
</tbody>
</table>
Reflections from NHS England
Cumbria and North East Region

Alison Smith
Deputy Director of Nursing
NHS England Cumbria and North East
Role of NHS England

– To lead and set up the Programme for preventing early deaths in people with learning disabilities
– Bringing people together to discuss action to take
– Providing support, advice, guidance and enable sharing of information
– Encouraging learning and change
Role of NHS England

Cumbria and North East

• First area to explore how to make a difference
• Trying to embed into mainstream business to ensure it is sustainable longer term
• Lead nurses in each CCG have agreed to be local area contacts
• Communication link between local work and regional and national NHS England work
• Share progress and learning with North colleagues
What has worked well

• Bringing organisations together to discuss the best way forward for this work
• Not just concentrating on reviewing deaths
• Thinking about how to make this work using existing systems and information already being collected
• Finding ways of knowing that we are making a difference e.g. NHSE quality assurance events and meetings
Challenges

• Ensure everyone understands and agrees to the process of reviewing early deaths, there are *so many organisations*

• Sharing information

• Truly involving people with learning disabilities and their carers and keeping them at the centre

• Reviewing deaths that happen in the community and not in a hospital
Top 3 Tips

1. Good communication
2. Making full use of existing processes
3. Focus on people
Next Steps

• Learn what we can do to make a real difference
• Put people with learning disabilities and their carers at the centre of the process of reviewing deaths
• Find out about the value of using information from incidents and complaints to learn more about preventing deaths
• Make all this business as usual
North East and Cumbria Learning Disability Network

Reducing premature mortality of people with learning disabilities

Judith Thompson, NE&C Learning Disability Network Manager,
North East and Cumbria Learning Disability Network Structure and Initiatives March 2016

Network manager & Quality
Assurance lead – Judith Thompson
Chair & Clinical lead – Dr Dominic Slowie
PA / Admin support – Kirsty Bell

North East and Cumbria Learning Disability Network

Area & Members

Clinical Commissioning Groups – x11
Local authorities – x13
North East and Cumbria Commissioning Support
Specialist Trusts - x3
Acute Trusts – x 10
Third Sector Providers
Specialised Commissioning – NHS England
Public Health England

Network manager & Quality
Assurance lead – Judith Thompson
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North East and Cumbria Learning Disability Network

Improving access & uptake of cancer screening services
Clinical lead - Dr Clare Scarlett (North Tyneside & Newcastle / Gateshead CCG)
Project manager – Julie Tucker

Good Access to Primary Services
Chair - Judith Thompson
Members - Primary Care facilitators

Access to Acute Network
Chair - Judith Thompson
Members - Acute liaison nurses
SRO - Dr David Hambleton Chief Op Officer (South Tyneside CCG)
Deputy SRO - Lesley Jeavons Head of Adult Services (Durham Council)
Transformation Board

Reducing premature mortality
Chair - Judith Thompson

Expectant mothers with a learning disability
Chair - Judith Thompson

Tackling dementia in people with learning disabilities
Programme lead - Judith Thompson

The learning disability RAIDR dashboard
Programme lead - Judith Thompson

Reducing obesity in people with learning disabilities
Programme lead - Judith Thompson

Cumbria satellite group
Chair - Judith Thompson

Workforce
Chair - Judith Thompson

Improving access to high street dentists for people with a learning disability
Chair - Judith Thompson

Joint Health and Social Care Self - Assessment Framework
Chair - Judith Thompson

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Setting up the pilot

• On the back of successful acute hospital pilot 2015

• Network provided established great links and relationships across health and social care sector

• Broadened remit and membership of steering group

• Communication

www.england.nhs.uk
North East and Cumbria Learning Disability Mortality Governance Structure - draft

North East & Cumbria Learning Disability Mortality Steering Group
- Develop reporting template for SABs/QSGs
  - Gather themes likely to occur (e.g. diagnostic overshadowing, communication) including challenges, barriers, timescales for completed actions
  - Prepare report for QSGs
  - Prepare annual report – public facing

Local Safeguarding Adult Boards
(Learning and Sharing Sub Groups linked to ‘prevention’ responsibilities)
Role of SABs:
- Receive anonymised learning points and actions
- Embed learning back into the system locally

Quality Surveillance Groups (CNTW & DDT)
Y1 – Q2, 3, 4 & 1
Y2 – Q2 & 4
Role of QSG:
- To be assured that learning is acted upon and resolve any barriers/challenges
- How does it hold ‘the system’ to account?
- Does the QSG report to region
Role of Steering Group

- Leadership
- Trust
- Critical role
- Evolving role
- Provides oversight and support
- Works out ‘how to do it’
- Lots of creative discussions
- Lots of challenging discussions
- Meets monthly
- Broad membership
- Provides assurance to others
- Embed sustainability
Role of Quality Surveillance Groups?

QSGs assure:

- Clinical effectiveness
- Avoidance of harm and risk to safety
- High quality care responsive to individual needs delivered with compassion, dignity & respect

It is the business of Quality Surveillance Groups to challenge all premature deaths
Role of Safeguarding Adult Boards?

SABs are responsible for:

- Working collaboratively to prevent abuse and neglect where possible

- Assuring itself that safeguarding practice is continuously improving and enhancing the quality of life of adults in its area.
Role of Safeguarding Adult Boards?

- SABs enable good communication
- SABs can maintain multi-agency oversight & effective collaborative working
- Testing out variety of different models:
  - Durham
  - Northumberland
  - Sunderland
Building the infrastructure

- Identifying potential Reviewers
- Identifying potential Local Area Contacts
- Identifying champions across organisations including in:
  - CCGs
  - General Practice
  - Acute Trusts
  - SABs
  - Adult Social Care
  - Specialist Learning Disability Trusts
  - ADASS
  - NHS England sub regions
Top 3 tips

- A clearly articulated communication plan.
- Engage people with learning disabilities and families early in setting up the work.
- Build on existing processes rather than developing new.
Thank you

Judith.thompson1@nhs.net
Robert Tunmore

Area Co-ordinator, LeDeR team
National implementation: Highlights and challenges

- Data sharing
- Aligning with other review processes
- Communication with all stakeholders
- Other pilot sites
Data sharing

• Approval process for Section 251 - NHS Act 2006 - Secretary of State for Health to make regulations to set aside the common law duty of confidentiality for defined medical purposes.

• Health Research Authority Confidential Advisory Group (CAG) debate on service evaluation or research review

• Development of secure web-based platform - ‘firewall’ security blocks
Data sharing

• Lack of clarity - responsibility for data

• Professional reluctance to share patient identifiable information after the person’s death irrespective of legal permissions / local agreements

• Challenges in overcoming systems problems in relation to bringing different health and social care systems and agencies together.
Data sharing

• Are existing data sharing agreements in place?
• Agreement for the purpose of mortality reviews
• LeDeR data sharing agreement template
• Seeking support from the Information Governance Alliance for guidance to local agencies
Aligning with other review processes

- Criminal proceedings,
- Disciplinary procedures,
- Employment law
- Systems of service and professional regulation.
- LeDeR reviews focus on learning & improvement – & not to hold individuals/organisations to account.
- To be able to learn from reviews – trust, safe experience, honesty, transparency and sharing of information to obtain maximum benefit from them.
- Guidance paper – Working with other investigations
Communication with all stakeholders

• Data sharing agreements and approvals

• Inform and keep people updated before notifications of deaths begin – who might people with learning disabilities & family carers go to for information & support? (eg groups they use now, bereavement services)

• Public communication not yet prioritised - delay deaths being notified until LeDeR able to act

• Focus on information sharing and updates to progress, rather than notification process
Communication with all stakeholders

• Communication Plan NHS England & Stakeholders
• Products/messages tailored to particular groups eg GPs, Coroners, family carers
• Local, regional and national communications
Communication with all stakeholders

- CCG chief officers
- Provider forums
- Partnership boards or equivalents
- Engagement teams within organisations
- Safeguarding boards
- Communication teams within organisations
- Regional people with learning disabilities forums
- Regional National Valuing Families Forum
- Chief Executives for Acute Trusts and Specialist Trusts
- Primary Care & community services
- Local authority lead officers
Other pilot sites

North
- Cumbria and North East (Cumbria, Northumberland, Tyne and Wear & Durham, Darlington and Tees)
- Lancashire and Greater Manchester
- Yorkshire and the Humber (North Yorks and Humber, South Yorks and Bassetlaw & West Yorks)
- Cheshire and Merseyside (Cheshire, Warrington and Wirral & Merseyside)

Midlands and East
- North Midlands (Derbyshire and Nottinghamshire & Shropshire and Staffordshire)
- Central Midlands (Leicestershire and Lincolnshire & Hertfordshire and South Midlands)
- West Midlands (Birmingham, Solihull and Black Country & Arden, Herefordshire and Worcestershire)
- East (East Anglia & Essex)

South
- South Central (Bath, Gloucestershire, Swindon and Wiltshire & Thames Valley)
- South West (Bristol, North Somerset, Somerset and South Gloucestershire & Devon, Cornwall and Isles of Scilly)
- Wessex
- South East (Kent and Medway & Surrey and Sussex)

London
- London
Ann Brown, Dr Emma Norfolk & Rachel Lucas

Operational Manager NHS Northumbria Healthcare FT
GP & Northumberland CCG learning disability clinical lead
Acute liaison nurse NHS Northumbria Healthcare FT
Northumberland & North Tyneside establishing a local review process
Working together
The challenges
Moving forward
North East & Cumbria Learning Disability Mortality Review

Learning & Sharing Event

Abuse don’t tolerate it don’t ignore it do report it!

One Team, One Aim, One Vision
The Pilot for Durham

- We first shared the report with our Board Members in January 2016.

- We also shared a letter from Dr Dominic Slowie with the Board. It helped us to think about what we should do in Durham.

- The Board said they wanted to know more about this and what the Board might need to do.

- We agreed to spend some time looking at how we could share learning in Durham from future reviews and how the Board might support it.
What did the Board do?

• We discussed the pilot at our Development Session in March 2016.

• We linked with Judith Thompson, Network Manager & Assurance Lead, North East & Cumbria Learning Disability Network for guidance.

• We wanted to get a view from our Board Members.

• We agreed to discuss it again at Board in April 2016.
We looked at our structure

Structure following March Development Session and subject to change in line with regular review.

Governance Structure 2016 - 2017

Local Safeguarding Children Board
Multi-Agency Partnership Boards
Healthwatch
Strategic Management Board
Overview & Scrutiny Committees

County Durham Safeguarding Adults Inter-Agency Partnership (SAB)
Independent Chair (Jane Geraghty)

Performance & Quality Group
Communication & Training Group
Learning & Improvement Group
Time limited Task & Finish Groups (as and when directed and agreed by the Board)

Connectivity Connectivity Connectivity Connectivity Connectivity Connectivity Connectivity Connectivity Connectivity Connectivity

Working Links to wider forums for example, Provider Forums, Local Information Sharing Group, Quality Surveillance Groups

Key: Working Relationships ←→ Reporting relationships
1 – I.e. Safe Durham Partnership, Health & Wellbeing Board, Children & Families Partnership
2 – Adult Wellbeing & Health

Structure following March Development Session and subject to change in line with regular review.
What did Adult Care do?

• It was agreed that the Better Health for People with Learning Disabilities Group should look at the recommendations and actions from the Inquiry.

• They agreed the Board should look at its role for receiving reports.

• They agreed a report should go to the Board in April 2016.

What worked well

- Knowing the remit, that the SAB was not responsible for undertaking reviews, helped us to look at it clearly.

- We looked at where the reviews should go, and thought one of working groups would be the best option, the Learning and Improvement Group.

- Discussing with our partners at an early stage to help to move it forward.

- We had opportunity to take part in a teleconference with other Safeguarding Adult Boards to get a wider view.

What didn’t work well

• Some people felt it was not the right time.

• We didn’t know if we would have the right people in place, with a Learning Disability Focus.

• Not knowing how many reviews and what this would mean in reality for the Board.

What did we agree?

• Its about governance and assurance.

• Our existing structure was the best option at this time.

• Its about scrutiny of actions and looking at the learning.

• It helps that some people sit on our Board and on other Boards/groups and strengthens links.

• The first report should go to our Board.

• To add the reports to our Learning & Improvement Group (LIG) Work plan as an action.

• To adapt the Terms of Reference for the LIG to ensure the ‘right people are in the right place, at the right time’.

• To review it again if there are higher numbers than expected.
What will help us now?

- To link with the steering group and Local Area Contact and firm up the process for Durham.

- Business support for the Board to develop the process to capture reviews and the learning.

- To test our agreed process.

- To review how it has worked and share what we have learnt.
Top Tips

• Don’t overthink it

• Think about resources and time, do you have enough of both? And consider the benefits of using what you have in place now (think in a LEAN way).

• The Board should only look at and monitor the learning and actions where there are multi-agency or wider implications - and not all reviews will result in actions.
Reflections from a Local Area Contact

Gill Findley, Director of Nursing North Durham and DDES CCGs
How I Came to be Involved....

• Judith attended QSG
• Good discussion about the role
• Similarities to SCR/DVR/ SIs
• I am inherently nosey and want to know what’s going on!
What Preparation Have We Done?

- Told the GPs and practice nurses that it’s coming
- Trained staff to do the investigations
- Worked with Director of Adult Care at Durham County Council
- Process agreed to inform LA every time we get a notification
- Discussed and Improving Health for people with Learning Disabilities group
- And........................
- We have our first case to review
What Next?

• Test out the process
• Walking through things hand in hand with the Local Authority
• Feedback to the CCG will follow the usual SI process
• Feedback to wider stakeholders will be via the learning lessons sub group of SAB and then to SAB
• Keep it simple and in line with existing processes

• Concerns:
• How the notification will work
• Workload for reviewing staff
Learning And Sharing Event from NE & Cumbria LeDeR Pilot
South Tees CCG Experiences

Barbara Potter Head of Quality and Safeguarding
Pam McNeice Clinical Lead Learning Disabilities
South Tees CCG Experiences

Clear Leadership with High level CCG Commitment

Strong links with Programme Leads and membership Steering Group

Robust Processes /Terms of reference

Communication

Experience – Transfer skills

Desire for Change

Sharing Knowledge
What's Working Well

- Right People?
- Knowledge of Area/links with other investigation processes
- Local Steering Group
- Support and collaboration with LeDeR Leads
- Systems and Information
- Robust systems to escalate concerns
What's Working Well

- Mortality Review adapted for local approach – Best fit.
- Communication ?
- Engagement Multi-professional Teams GP’s
- Links to local patient groups
The Challenging Areas

- Gaining Full sign up and commitment to LeDeR
- Timely cascade of Information
- Consent
- Information Governance Section 251
- Access to quality data/standard set - Quality
- Financial/resources
- Workforce Development/Reviewers
The Challenging Areas

- Managing sensitive information
- Families & carers
- Family & carer experience capturing views
- Supervision/support
- Peer support/supervision
Moving forward

- National Mandate – Legal Frameworks to improve Governance Structures
- Local & regional support for reviewers – peer support – Workforce development (register)
- Learning from process? Learning into Mortality Steering Group
- Identify and Share Best practice
- Increase family & carer Involvement in Process
3 Top Tips

• Positively promote the Pilot – changes minds!
• Access Support from the National Team & Network Mortality Review Steering Group
• Share experiences
Reviewers Reflections

Alison Forsyth
Learning Disability Liaison Nurse

Healthcare at its very best - with a personal touch
Our role and the organisation we work for

Learning Disability Liaison Team.

The Newcastle upon Tyne Hospitals NHS Foundation Trust.

Develop a Trust wide pathway.

Establishment of a review panel.

Healthcare at its very best - with a personal touch
**Highlights**

- Good Care.

- Positive engagement from staff.

- Ownership of Change.

**Challenges**

- Not capture all people with a learning disability.

- Family/carer involvement.

- Deprivation of Liberty Safeguards.

- Multi-agency partnership working

*Healthcare at its very best - with a personal touch*
Would we do anything differently?

- Development of a new pathway.
- Organisation friendly ‘do it review it!’
How to move it forward

- Awareness raising.
- Engagement with child death review process.
- Continue to evaluation and develop the process.
Overall experience

- Positive.
- Lots of learning.
Three top tips

- Importance of team approach.

- Don’t underestimate emotional effect.

- Importance of having clear process for gathering of information.
Healthcare at its very best - with a personal touch