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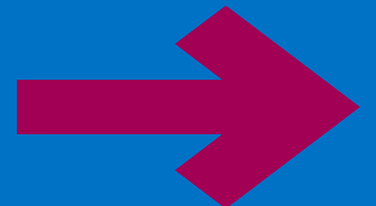
People with a Learning Disability: Living Long & Healthy Lives – Premature Mortality Reviews & why this is important for Safeguarding

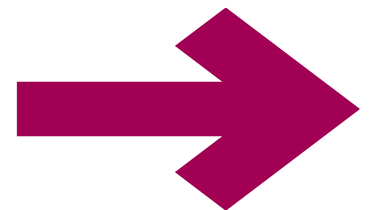
North Lincolnshire Safeguarding Adults Board Annual Conference

5th October 2018



hello my name is...

John Trevains



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People with learning disabilities have poorer physical and mental health than other people.

This is not an inevitable outcome.

National context (1) -LeDeR programme aims

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The programme aims to:

- Identify the potentially avoidable contributory factors related to deaths of people with learning disabilities
- Develop local and national action plans to improve health and social care services for people with learning disabilities
- Reduce health inequalities & premature mortality

National context (2) – Current data

- Public Health England/ University Bristol predict circa 3400 reported deaths per year – recently updated data
- The most recent annual report 2017 - 18, informed us, that from the limited cases reviewed median age of death is **23** years younger for men and **29** years younger for women than general population.
- Wider studies have shown a median age of death from **53 to 57** years of age

Findings from national report : Demographic and other details (July 2016 – Nov 2017)

- Males 57%; females 43% (n=1,311)
- White ethnic background 93% (n=1,145)
- Usually lived alone 9% (n=1,158)
- Had been in an out-of-area placement 9% (n=1,158)
- Died in hospital 64%, compared with 47% in the general population (n=1,244).

Findings: age at death

- Median age at death 58 years
  (range 4-97 years) (n=958)
  males – 59 years   females – 56 years

- Compared with the general population, the median age of death for people with LD is:
  23 years younger for men 29 years younger for women

- Over a quarter (28%) of deaths were of people aged under 50 years –compared with 5% in the general population of England and Wales aged four years and over who died in 2016

Findings: cause of death

- Most common individual causes of death (n=576)
    - Pneumonia 16%
    - Sepsis 11%
    - Aspiration pneumonia 9%

- Most common underlying causes of death
    - Diseases of respiratory system: 31%
    - Diseases of circulatory system: 16%
    - Neoplasms (cancer): 10%

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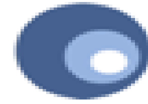

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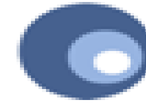
Assessment of care: excellent care

Of 103 completed reviews:

Reviewers graded 45 (44%) as ‘excellent care’

‘The family actively participated in discussions with the multidisciplinary team and in planning Jenny’s end of life care. This was facilitated by a high level of communication between the many acute, critical care, palliative care and community professionals involved in her care as well as by a clear and organised plan for managing her transfer back to the care home and her management there.’



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Assessment of care: falling short of good practice

Of 103 completed reviews:

Reviewers graded 10 (10%) as falling short of current best practice

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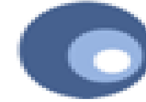

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Findings: learning identified

The most commonly reported learning and recommendations were made in relation to the need for:

a) Greater inter-agency collaboration, including communication
b) Greater awareness of the needs of people with learning disabilities
c) Greater understanding and application of the Mental Capacity Act (MCA)

LeDeR Recommendations

1. Strengthen collaboration, information sharing, and effective communication between different care providers or agencies.

2. Push forward the electronic integration of health and social care records to ensure that agencies can communicate effectively, and share relevant information in a timely way.

3. Health Action Plans should be shared with relevant health and social care agencies.

4. All people with two or more long-term conditions should have a local, named health care coordinator.

LeDeR Recommendations

5. Providers should clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision.

6. Mandatory learning disability awareness training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families.

7. There should be a national focus on pneumonia and sepsis in people with learning disabilities, to raise awareness about their prevention, identification and early treatment.

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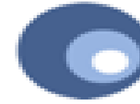

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LeDeR Recommendations

8. Local services to strengthen their governance in relation to adherence to the MCA, and provide training and audit of compliance 'on the ground' so that professionals fully appreciate the requirements of the Act in relation to their role.

9. A strategic approach is required nationally for the training of those conducting mortality reviews or investigations, with a core module about the principles of undertaking reviews or investigations, and additional tailored modules for the different mortality review or investigation.

Recently published ministerial response to address recommendations

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Challenges to achievement

- Notifications above previous estimates – current PHE/Bristol modelling predicts 3400 per year, against initial estimates of circa 3000.
- There is significant variation in time taken to complete reviews. The review process is complex
- Availability of skilled reviewers, influenced by numbers enabled to be released from duties to complete reviews.
- Though significantly increasing, low numbers of reviews completed limits potential for learning to be achieved and local systems improved to reduce premature mortality.

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National high level actions

- Additional funding to support areas - £1.4million distributed
- NHS England through HQIP are working to further adapt the current review methodology with University of Bristol and align with SCJR programme
- NHS England Sustainable Improvement Team are working with regional coordinators to support improvements in efficiency of delivery at local steering group level
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- NHS England working with senior national regional leaders to reinforce messages to local areas to actively support the review programme in line with NQB Learning from Deaths (2017) guidance and National Planning guidance 2018/19

Learning into action – proactive work to address identified mortality themes (1)

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- Most common individual causes of death (n=576 - 2017 Annual Report data) Pneumonia 16%; Sepsis 11%; Aspiration pneumonia 9%

- Additional learning from mortality reviews informs us that issues such as application of the Mental Capacity Act, constipation, epilepsy and failure to recognise deterioration are significant factors in avoidable premature mortality

- NHS England Learning Disabilities programme initiated a group to better coordinate focussed responses to premature mortality review learning. The "Learning into Action" work stream coordinates a coalition of ALB's, provider Trusts and stakeholders to identify current and/or produce new packages of best practice measures / urgent health interventions for health and social care.

Learning into action – proactive work to address identified mortality themes (2)

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- Specific work on early detection of symptoms of sepsis, early warning signs recognition (NEWS2), dysphagia, pneumonia, constipation, epilepsy and the effective use of Mental Capacity Act in urgent care settings is underway.

- Flu Vaccinations - NHSE working with Public Health England developed plans to prepare for promoting vaccination for people with a learning disability in readiness for this this winter. This work is inclusive of multi agency communication, improved prescribing guidance for practitioners, liaison with pharmacists and creation of easy read information

Learning into action – proactive work to address identified mortality themes (3)- Sepsis

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- National workshop focussed on Learning Disabilities and Sepsis. This workshop brought together frontline practitioners from acute and primary care , stakeholder groups such as MENCAP and VODG alongside other NHS ALB's.
- A number of best practice approaches were shared , from easy read guidance on detecting sepsis, triage guidance through to educational programmes for residential services regarding recognition of early warning signs and deterioration.
- The group is meeting again to progress this work, develop work on recognition early warning signs for people with learning disability and share nationally.

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Learning into action – proactive work to address identified mortality themes (4)

- Regarding how to best share improving practice information we have developed a web based platform for sharing this knowledge across professional and stakeholder networks.

- We are working to launch this platform in Autumn 2018 and promote a self sustaining community of practice .

Learning into action – proactive work to address identified mortality themes

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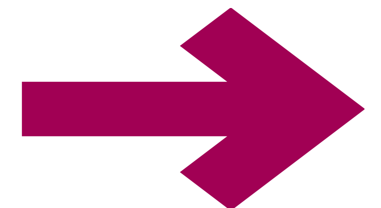
- Ongoing related heath inequality work regarding Annual Health Checks, STOMP, CTR's , RightCare & NHS Digital Flagging Project
- The group will be providing the Care Minister with an annual report on progress
- National level workshop being scheduled for February 2018
  - Bringing professionals and commissioners from across the system together
  - Examples of best practice
  - Workshops on how to facilities this approach within local steering groups
- **To do next : local area learning into action networks – good work started in the North!**

Care and Treatment Reviews – Children & Adults

- CTR’s & CETR’s
- Good progress made but more required
- Asks questions about physical health
- Preadmission CTR’s prevent unnecessary admission – **Especially for children**
- Consistency in quality requires focus
- Quality Assurance Framework and toolkits available



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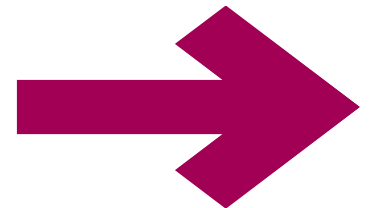
GP Registers and Annual Health Checks

- 2010 – IHAL review of the evidence shows that health checks improve:

  - the detection of unmet, unrecognised and potentially treatable health needs (including serious and life threatening conditions such as cancer, heart disease and diabetes)

  - targeted actions to address these health needs



Right Care Pathways and commissioning health access

- Commissioning Health access for people with learning disabilities
- Pathways in long term conditions with commonly reported poor outcomes for people with a learning disability.
- ***Pathways being published include Diabetes, Epilepsy, Constipation, Dysphagia & Reasonable Adjustments***
- All focus on reasonable adjustments

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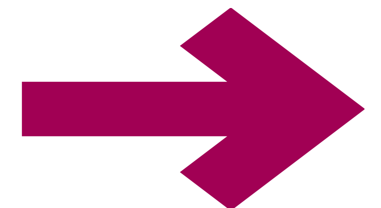

STOMP

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Public Health England says every day about 30,000 to 35,000 adults with a learning disability are being given **psychotropic** medicines when they do not have a diagnosed mental health condition. This is often to manage behaviour which is seen as challenging.

It includes medicines used to treat psychosis, depression, anxiety, sleep disorders and epilepsy medication when it is only used for its calming effect, rather than to treat epilepsy.

Unnecessary use of these drugs, puts people at risk of significant weight gain, organ failure and even premature death.

What you can do – please take back to your areas of work

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- Focus on health access
- Focus on learning disabilities patient safety
- Reasonable adjustments to support access
- GP Registers and Health Checks
- STOMP
- Focus on early warning signs – deterioration
- Support mortality review work