Reducing Inequity around Legislation
Learning and Good Practice

Maria Foster, Health Inequalities Senior Manager - North East & Yorkshire
Learning Disability And Autism Programme

Inequity in access to services

Leder continues to highlight concerns across a number of areas which impact on mortality & health and wellbeing. From the reviews of deaths we continue to evidence:

- Delays in diagnosing and treating illness
- Delay in appropriate investigations
- Delay in the timely provision of medical care
- Delay in processes related to the Mental Capacity Act.
- A lack of Reasonable adjustment in line with the Equalities Act
- Appropriateness of DNACPR orders

Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) Orders

Learning

While most DNACPR orders are in place appropriately there is concern about several issues.

These include:

- Lack of awareness by the person or their NOK, that an order had been put in place
- Lack of use of the Mental Capacity Act, to confirm the person didn't have capacity to be involved in the decision and not using the Act to make a Best Interest Decision
- Some orders were not reviewed and had been in place for years, some were not accurately documented
- The clinical rationale for its application was the person had a learning disability, down's syndrome or cerebral palsy
- The frailty framework produced as part of the COVID created a bias, against those with a learning disability, and increased diagnostic overshadowing and inappropriate application of DNACPR.
- CQC have now investigated the implementation of such orders and both National Directors and themselves have requested all DNACPR orders are reviewed to ensure appropriateness of those in place.

DNACPR links:

https://www.england.nhs.uk/wp-content/uploads/2020/09/C0713-202021-General-Medical-Services-GMS-contract-Quality-and-Outcomes-Framework-QOF-Guidance.pdf

Protect, respect, connect – decisions about living and dying well during COVID-19 | Care Quality Commission (cqc.org.uk)

Learning Disability England DNACPR Support Pack

Deaths of people with learning disabilities from COVID-19.pdf (bristol.ac.uk)

Death Certification
MCCD

Avoidable medical causes of death

- In 2019 people died from an avoidable medical cause of death twice as frequently as people in the general population (44% vs 22%).

- The greatest difference between people with a learning disability and the general population was in relation to medical causes of death, which are treatable with access to timely and effective healthcare.

- 34% of deaths were from treatable medical causes, compared to 8% in the general population – a four-fold difference.

- The age-standardised avoidable mortality rate for people with a learning disability was 520 (per 100,000) compared to 227 for the general population.

- The majority of this excess, mortality was due to treatable, rather than preventable, causes.

- Treatable causes accounted for 403 per 100,000 deaths in people with a learning disability, compared with 83 per 100,000 deaths in the general population.

Learning

Medical Certificate of Cause of Death

- Continued inaccuracy of the coding of the underlying causes of death continue to be seen in the deaths reviewed within LEDER alongside poor quality in some cases
- This includes recording of learning disability, Downs syndrome and cerebral palsy, as though it's a direct contributing factor or the direct primary cause of death of the person (diagnostic overshadowing)

  Examples seen include: 1a Sepsis, 1c Learning Disability / 1a Pneumonia, 1b Downs syndrome
- In 2019 Leder highlighted Down's syndrome was recorded 655 times in part 1A on death certificates as the underlying cause of death.
- Coding underlying causes of death as being from congenital and chromosomal causes, conceals the more specific causal sequence of events leading to the person's death.

Coroners

- Having a learning disability you are less likely to have your death reported to the coroner (32%) than people in the general population (41%).
- However more likely to have a post-mortem (50%) than those in the general population (39%) and morel likely to have an inquest (28%) in comparison to a those in the general population (13%).

***Despite this not all deaths are referred to the Coroner which should be and appears linked to the quality and accuracy of causes of death cited on the MCCD. It is hoped with the recruitment of medical examiners that both death certification and referral to coroner, will improve in respect of patients with a learning disability**

Mental Capacity Act 2005

Purpose of the Act

Protects the person's rights by making sure people are acting in the person's best interests.
Makes sure that the person's wishes around their own care are considered
Ensures effective and timely diagnosis and treatment are provided.
Makes sure clinicians are fulfilling their duty of care obligations to the person.

Benefits of the Act

Minimises negative impact on health and wellbeing and mortality.
Prevents late presentation of undiagnosed or untreated disease.
Reduces the possibility of someone being in hospital for longer than they need to be.
Reduces risk of poor clinical outcomes and additional disabilities
Delivers care which is in line with clinical guidelines and best practice.

LEDER reviews have evidenced that applying the Mental Capacity Act 2005, to physical health issues is a significant factor in reducing or preventing avoidable death's

Most reviews have evidenced good practice exists around the use of the Mental Capacity Act 2005.

Key Actions & Good Practice

- Be aware of missing a serious illness.
- Don’t ignore symptoms or assume its because of someone’s learning disability.
- Be sure the person has the correct information to make decisions about their treatment or care
- Make sure the information is explained or presented in a way that is easy to understand
- Make sure the person has a hospital passport. Makes sure others read and act on it.
- Make sure the person has an advanced care plan in place where appropriate

- Always ensure someone who knows the person well, relays information and supports the persons where appropriate.
- Think about any reasonable adjustments needed to help with diagnosis and treatment.
- When a mental capacity assessment or a best interest decision is needed, remember this should be decision specific.
- Make sure decisions and process are followed and recorded
- When making decisions, consider whether it needs to be made immediately or can wait, especially if the person is likely to be able to decide later. This must never compromise diagnosis, treatment outcome or care.

Where can I find out more?

An interactive decision-making tool to aid understanding and application such as:
www.github.com/sabpnhs/mcatool

NHS England safeguarding app/MCA section.
www.myguideapps.com/nhs_safeguarding/default/

Mental Capacity Act Code of Practice.
www.gov.uk/government/publications/mental-capacity-act-code-of-practice

Information about reasonable adjustments.
www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments

Information about advanced decision making.
www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment

The “Mental Capacity Act” reference book - iPhone app.

www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/

www.bristol.ac.uk/sps/news/2018/leder-report.htm

On reflection

Ensuring that good practice exists in respect of the following will make significant differences to the lives of people with a learning disability:

- Good use of the MCA when applicable
- Use of reasonable adjustments to facilitate access to care and treatment
- Improved coding and quality of death certificates and reporting deaths to coroner
- Ensuring that DNACPR orders are appropriate and in place
- Documentation is improved across all aspects of above
- Increased awareness of the needs of people with a learning disability and Autism