Learning Disability Mortality Review LeDeR

Why the LeDeR Programme is so important

https://youtu.be/g-lgegZK4Xo

LeDeR Annual Report 2018

The LeDeR Annual Report is about people who have died, they were people who were loved, cherished and whose deaths have been heart-breaking for their family and those who loved them.

Sometimes we can forget that there are people at the heart of these reports and in the mass of data there is a danger that people can become numbers.

LeDeR Annual Report

This Annual Report presents information about the deaths of people with learning disabilities aged four years and over, with a particular focus on deaths reviewed and completed during 2018.

In **2018** approximately **86%** of people with a learning disability who died were referred to the LeDeR programme.

90% of people referred to the programme were of **White British** ethnicity

The **median age** for people referred to the programme was **59 years**. 58% were male and 42% were female.

The data suggests a disparity in the age of death for people with a learning disability and the general population – **23 years for males and 27 years for females.**

Key Points

- There was rise in deaths through autumn and early winter
- The proportion of people with learning disabilities dying in hospital was 62%, the general population is 46%
- Reviewers found in the majority of cases the DNACPR orders were appropriate, however 19 reviews reported that the term ‘learning disabilities’ or ‘down syndrome’ was given as the rationale for the DNACPR order
- The most common cause of deaths for people referred to the programme were –
    - Pneumonia
    - Aspiration pneumonia
    - Sepsis
    - Dementia
    - Ischaemic heart disease
    - Epilepsy

Best Practice

Over 33% of reviews reported one or more examples of best practice. These were frequently in relation to –

- Strong, effective inter-agency working
- Person-centred care
- End-of-life care

Indicators of poor quality care

- Transition planning for those moving from children's to adults services
- Delays in diagnosis
- Delayed discharge from hospital
- Delayed recognition of approaching end of life
- Information sharing
- Staff resources and skills
- Lack of ‘joined-up’ working and co-ordination of care

Multi-agency Reviews

10% of referral resulted in a multi-agency review. The panel found –

- 68% of deaths were not potentially avoidable
- 19% of deaths were potentially avoidable
- 13% of deaths, a unanimous decision could not be made, or were unanswered

Lessons learnt were identified in 70% of multi-agency reviews.

Key Recommendations

- Ensure staff are appropriately trained on how to support people with a learning disability
- Ensure services work together more effectively and share information
- We must ensure we recognise when a person is becoming unwell or their health is deteriorating
- Empower families to speak up if they have concerns about their relatives death
- Consistent use of terminology particularly in relation to the use of ‘learning disability’

Key Recommendations

- Try and engage with people with learning disabilities from ethnic minorities
- Better processes for people with a learning disability when transitioning between children and adult services
- People should not have their cause of death described as being because of their learning disabilities
- People should not be stopped from having treatment because they have a learning disability
- We should check that DNACPR forms are correctly completed