Joint Statement from the Oxfordshire Transforming Care Partnership Board: Oxfordshire review into the deaths of people with learning disabilities 2017-18

Statement from the co-chairs of Oxfordshire's Transforming Care Partnership Board

"While we have known for many years that people with learning disabilities die earlier than the general population, the Learning Disability Mortality Review report made for grim reading and was deeply upsetting.
As co-chairs of Oxfordshire's Transforming Care Partnership Board we feel it is important that we make public the work that is being done locally to explain how deaths of people with learning disabilities are investigated in our county. Despite the lower numbers of deaths reviewed, it is clear that there is still much work to be done to address these inequalities. We are however pleased that all deaths are now being reviewed in such detail. We welcome the recommendations contained in this report and the spirit of transparency and openness in which it has been shared."

Gail Hanrahan (Oxfordshire Family Support Network) and Paul Scarrott (My Life My Choice)

Background

In 2016 Oxfordshire Clinical Commissioning Group carried out a review of the deaths of all people with a learning disability in Oxfordshire who died between April 2011 and March 2015[1].

The review found that:

- Care coordination was essential in order to deliver the best care and treatment, including strong partnerships between services and family;
- Comprehensive health checks needed to be delivered more consistently;
- All services needed to understand mental capacity assessments better;
- Services needed to work harder on making adjustments for people with specific additional needs.

Following the review, the Oxfordshire Safeguarding Adults Board (OSAB) set up the Oxfordshire Vulnerable Adult Mortality Group (VAM). The VAM reviews the deaths of every person (including children and young people) with a learning disability in Oxfordshire, unless there is a review already being carried out by another organisation (e.g. a coroner's review).

The VAM reports to OSAB and to the national Learning Disability Mortality Review (LeDeR) programme.

In June 2018 the Oxfordshire Safeguarding Adults Board published its annual report on the deaths of Oxfordshire people with a learning disability between April 2017 and March 2018.

[1] This work was done in response to the "Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015" (Mazars, December 2015)

The reviews looked at the circumstances of each death. They focussed on understanding why the person died, the care and treatment they received and whether anything could have been done to prevent their death.

17[2] reviews were carried out in 2017-18. The reviews suggest that people with learning disabilities in Oxfordshire:

- Generally die of the same conditions as the wider population (the leading causes of death were pneumonia, cancer and heart disease).
- Die younger than the wider population, although over half died aged 60 or above and a third died aged 70 or above;

The review found some good practice and some areas for improvement. The key recommendations from the report are that health and social care organisations need to:

- Strengthen links between support workers, families and health teams;
- Ensure appropriate use of mental capacity assessments;
- Make sure health assessments are being done, that health actions plans are produced and that these lead to proactive care;
- Improve the way services support people at key points of transition, particularly where this involves a person moving from child to adult services.

The findings and recommendations of the report have been shared with providers, commissioners, representatives of people with learning disabilities and their family carers via the Transforming Care Partnership Board.

The Board will make sure that the learning from the reviews is shared widely and that the actions needed to improve care are included in the Transforming Care Plan (or in other service improvement plans, e.g. the Oxfordshire CAHMS Transformation Plan). The Board will also review the recommendations set out in the national Learning Disability Mortality Review Annual Report 2017.

National learning from the LeDeR Programme

The national LeDeR programme collates the findings of the local reviews. So far LeDeR has been informed of the deaths of 1,311 people with learning disabilities across the country, with 103 reviews completed.

The most commonly reported causes of death nationally are:

- Respiratory Disease 31%
- Circulatory Disease 16%
- Other underlying causes 11% (e.g. Epilepsy, Dementia, Downs Syndrome, Sepsis)
- Cancer 10%

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

[2] 29 people with a learning disability who were known to health or social services died in 2017-18. VAM did not review 12 people because their deaths were already being reviewed by other agencies, e.g. the coroner.

- Collaboration and communication between organisations;
- Awareness of the needs of people with learning disabilities;
- Understanding and application of the Mental Capacity Act (MCA).

The report points out that most of the learning points from the LeDeR reviews have been identified before. This is important as it suggests that at the national level services are not changing quickly enough to deliver better care for people with learning disabilities.

Local learning from the VAM Group

The Oxfordshire VAM was notified of 29 deaths of people with learning disabilities in 2017-18. 17 reviews were completed.

Local findings differed from the national picture. It is important to note that as there were small numbers locally it is not possible to draw statistically significant conclusions.

The most common causes of death locally were:

- Pneumonia
- Cancer
- Cardiac disease

The average age of death for those people who were reviewed was 60. Nationally this was 58.

The most common place of death was hospital, followed by home and hospice. The reviews found:

- Examples of good joint decision making;
- Evidence of working in partnership with families;
- Evidence of staff knowledge about the person's likes and dislikes;
- Advocacy for key decisions was in place in over half of cases;
- Evidence of adjustments being made in some cases;
- Pre-existing end of life plans had been completed in over half of cases.

However, the reviews also found that:

- Care coordination was lacking in some cases;
- Mental capacity assessments were frequently not clearly documented;
- Care and treatment could have been more proactive;
- Transition from child to adult services can be problematic.

The VAM report shows that further action is needed in Oxfordshire to improve health and care services for people with learning disabilities. People who work in services need to be aware of the actions they can take to improve care and of the factors which mean people with learning disabilities can be at risk of poor health and / or die too young.

The links between support workers, families and health teams need to be strengthened. Health assessments like annual health checks must be carried out. They must result in health action plans which help to make sure people get the proactive care they need, for example cancer screening.

Further work needs to be done to make sure professionals are carrying out mental capacity assessments and clearly recording the outcome.

Transitions, particularly where these involve moving from children's to adults' services, continue to be difficult for people with learning disabilities, their family carers and the professionals they work with. This can put people's health and care at risk and more work needs to be done to improve how people move between services at key points in their lives.

Next steps

The learning from the VAM report is being shared through the Oxfordshire Safeguarding Adults Board, the Transforming Care Partnership Board and the organisations who are represented, including Oxfordshire Family Support Network and My Life My Choice.

The learning from the report and the associated actions will be built into the Transforming Care Plan and other plans which are aiming to improve services for people with learning disabilities.

Oxfordshire CCG (which coordinates VAM reviews) is also talking to representatives of people with learning disabilities and family carers about how 'experts by experience' (people with lived experience of learning disability and their family carers) can be more involved in the review process, particularly when the person who has died does not have any immediate relatives. This is to make sure that the insight and expertise of people with lived experience informs the review and any subsequent recommendations for improving care.