Learning Disabilities Mortality Review
(LeDeR) Programme

REPOSITORY ANALYSIS 2015 – 2017

This report highlights themes identified in the key findings and recommendations from the case reviews included in the repository for the period January 2015 to December 2017. The case reviews pertain to deaths and serious incidents involving people with learning disabilities from across England. They include Safeguarding Adult Reviews, Serious Case Reviews, Serious Incident Reports, and Ombudsman reviews.

The repository includes summaries of each review and links to the original documents. These summaries formed the basis of the analysis here. The names used in the analysis are those used in the original reviews. These were pseudonyms in the main, with real names used where requested by the individual concerned or their families.

The report contains 2 sections:

(1) KEY FINDINGS. These include examples of specific failings in the care of people with learning disabilities.

(2) RECOMMENDATIONS. These are calls for action that are broad in scope and apply beyond the specific case under consideration.

KEY FINDINGS

Learning points from the repository are related to failures in the care of individual people with learning disabilities, and the learning that has been gained from these. The learning from the reviews fall into six main themes:

- Interagency communication and working
- Professional practice
- The direct provision of care
- Communication with families, carers and people with learning disabilities
- Adherence to guidance and legislation
- Systems issues

Interagency communication and working

The most frequent theme was interagency communication and working (23 learning points). Within this theme the main issues are:

- A lack of multi-agency communication and planning, specifically around weight, behaviour, and transition from child to adult services.
- Poor communication between different organisations about health and care needs.
- A lack of communication about concerns over risk, leading to safeguarding issues.

Examples from learning points in the repository:

Changes in Mr J's behaviour and health should have prompted a multi-disciplinary meeting, however, inter-agency communication and planning was poor.

Some agencies, including police and probation services failed to share information or raise appropriate safeguarding referrals when risk was identified

Professional practice

The second most frequent theme was professional practice (in 22 learning points). Within this theme the main issues are:

- Failure to follow good practice or made poor decisions. This was usually due to insufficient or ineffective use of assessment and care plans, health action plans, and hospital passports.
- An undue reliance on restraint in managing behaviour.
- Underuse of historical information about challenging behaviour to inform decision-making.
- Poor record keeping by care staff.
- Desensitisation to aggressive behaviour resulting in violent acts going unreported.

Example from a learning point in the repository:

The Annual Health Check by the GP identified obesity as an issue, but no actions were agreed to address this.

Communication with families, carers and people with learning disabilities

Communication with families, carers and people with learning disabilities was a persistent theme (in 17 learning points). Within this theme the main issues are:

- Practitioners not communicating with family or representatives about the care needs of people with disabilities.
- Staff and professionals unclear of the need to involve or inform family members.
- Ineffectual support for parents with learning disabilities.
- The need to understand complexities presented by culture and diversity when working with families.

Example from a learning point in the repository:

In response to difficulties in communication, there should have been greater involvement of Mr J's parents who had useful knowledge on how to communicate with Mr J about when he was in pain.

Direct provision of care

Another frequent theme was the direct provision of care (in 17 learning points). Within this theme the main issues are:

- Clinical failure in the treatment of people with learning disabilities while in hospital. These were all in acute care and included missed assessments or tests, managing epilepsy and delays in giving fluids or nutrition.
- Overlooking physical illness and inappropriately assuming that a problem was due to the person having learning disabilities, often referred to as diagnostic overshadowing.
- Failure by the care provider to meet the care needs as obligated in the contract.

Example from a learning point in the repository:

The hospital report notes there may have been diagnostic overshadowing in A's treatment, due to the presence of learning disabilities.

Systems issues

Systems issues were identified in 16 learning points. Within this theme the main issues are:

- Insufficient reviewing or monitoring of care placements by commissioners of care.
- Care plans that were ineffective, unsubstantial, or not reviewed on a regular basis.
- Long stays in Assessment and Treatment Units.

Example from a learning point in the repository:

There does not appear to have been any regular supervision or monitoring of staff despite a support plan and numerous concerns being raised by Mr C's parents, about attitudes, behaviour and quality of care and support.

Adherence to guidance and legislation

Another frequent theme was adherence to guidance and legislation relating to the care of people with learning disabilities (in 10 learning points). Within this theme the majority were references to the Mental Capacity Act 2005 including**:**

- Under-use of assessment of capacity.
- Not employing an independent advocate.

- A lack of understanding of the Act by practitioners.

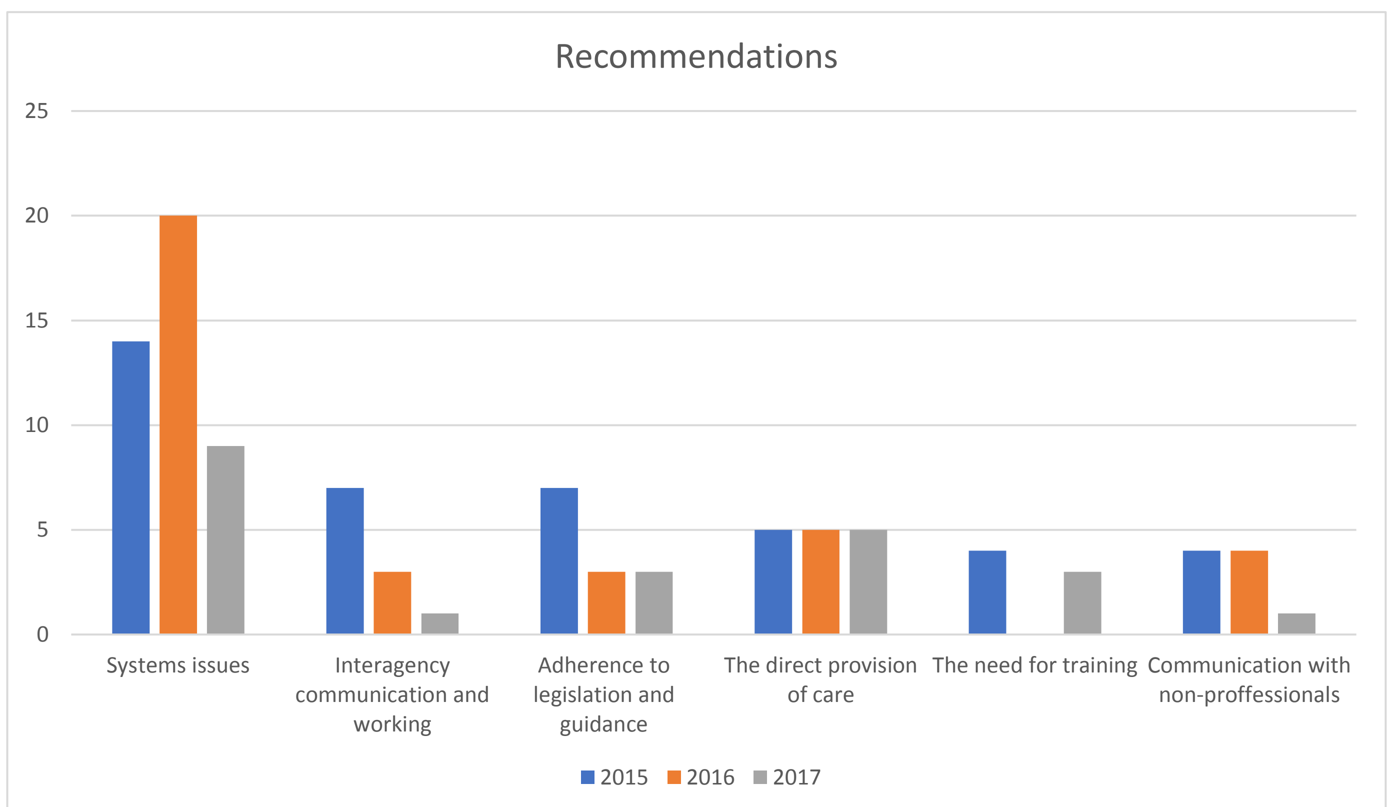
Example from a learning point in the repository:

There was a lack of a consistent approach towards the requirements of the Mental Capacity Act by practitioners working with L, specifically regarding weight management and delaying telling him about the death of his father.

RECOMMENDATIONS

Recommendations are calls for action that are broad in scope and apply beyond the specific case under consideration. The recommendations from the reviews in the repository fall into six different themes:

- Systems issues
- Interagency communication and working
- Adherence to legislation and guidance i.e. the Mental Capacity Act 2005
- The direct provision of care
- The need for training
- Communication with non-professionals i.e. families, carers, and people with learning disabilities



Systems issues

The most frequent recommendation made was in relation to systems issues (41 recommendations). This included recommendations that relate to the introduction, change or improvement of processes and practices. They proposed improvements to:

- Monitoring and auditing of contracts and the accountability of providers. Specifically, this refers to hospital and out of area placements.
- The effective commissioning of care by commissioners and ensuring that the care provided is of a high quality.

- Systems that ensure effective safeguarding of all children, including those with learning disabilities.
- Appointing a named care coordinator or lead health professional for each person with learning disabilities and complex health needs.
- The introduction of effective safeguarding policy by all responsible organisations, that incorporates an immediate response to a safeguarding incident and a longer-term strategy and provides clearly defined roles with a lead professional responsible for adult safeguarding.
- The joint review of health and social care needs on an at least annual basis.
- More effective use of learning disabilities liaison services.

Examples of recommendations from the repository:

Councils as care commissioners ensure effective systems to provide clear care plans, monitor services delivered, hold providers to account, check achievement of required outcomes and respond to quality concerns.

All 18+ adults with learning disabilities and complex support needs have a named care co-ordinator and their health and social care needs jointly reviewed on at least an annual basis

Interagency communication and working

The need for improved interagency communication and working was identified in 14 recommendations. Recommendations referred to the need for:

- Care coordination supported by information sharing between professionals and across services.
- Regular multi-agency reviews.
- All relevant parties to be made aware of discharge information following a patient's stay in hospital.
- Agencies to improve information sharing about safeguarding concerns. This includes following up safeguarding alerts across organisations and the sharing of relevant background information.

Example of recommendation from the repository:

Current arrangements for information sharing between agencies should be assessed to find ways of increasing the identification and sharing of relevant background social information about pregnant women and their partners.

Adherence to legislation and guidance

Adherence to current legislation and guidance, with a particular focus on the Mental Capacity Act, was also a common theme (14 recommendations). Recommendations suggested:

- Improving awareness of the Mental Capacity Act to ensure it becomes central to professionals' working lives.
- A better understanding and application of when an assessment of capacity is required.
- Greater use of an independent advocate.
- Further or improved training for staff about the Mental Capacity Act.

- Adherence to guidance on Deprivation of Liberty Safeguards.

Example of recommendation from the repository:

Appropriate bodies review the level of confidence and understanding amongst practitioners and managers regarding when and how to undertake Mental Capacity Act assessments where there is doubt about capacity.

The direct provision of care

The direct provision of care for people with learning disabilities was a significant theme (11 recommendations). Recommendations included:

- The need for personalised care to reflect individual needs.
- Care and care plans needing to be dynamic to reflect changing needs.
- Practitioners to ensure they are careful to follow instructions relating to nutrition and fluid intake.

Example of recommendation from the repository:

Quality checks and supervision records should examine food diaries to ensure that they are compliant with individual's eating and drinking guidelines.

The need for training

There were several recommendations that called for further or enhanced training for staff (9 recommendations). Issues identified included the need for training about:

- Bowel health
- Dysphagia
- Learning disability awareness

Example of recommendation from the repository:

Ensure comprehensive learning disability awareness training for hospital staff is provided.

Communication with families, carers and people with learning disabilities

Some recommendations referred to the need for regular or improved communication with families, carers and/or people with learning disabilities (8 recommendations). Specifically, they proposed:

- Regular consultation with families or representatives about the needs and wants of people with learning disabilities and the suitability of care placements.
- Care coordinators recognise the value and skills of people's families or representatives.
- Understanding by agencies of the impact of mental health issues on the ability of families and service users to communicate their situation and needs.

Example of recommendation from the repository:

Care coordination is supported by record keeping and information sharing across professionals and services and that people's families or representatives are regularly consulted.