Learning Disabilities Mortality Review
(LeDeR) Programme

REPOSITORY ANALYSIS 2018 – 2019

This report highlights themes identified in the key findings and recommendations from the case reviews included in the repository for the period January 2018 to December 2019. 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:

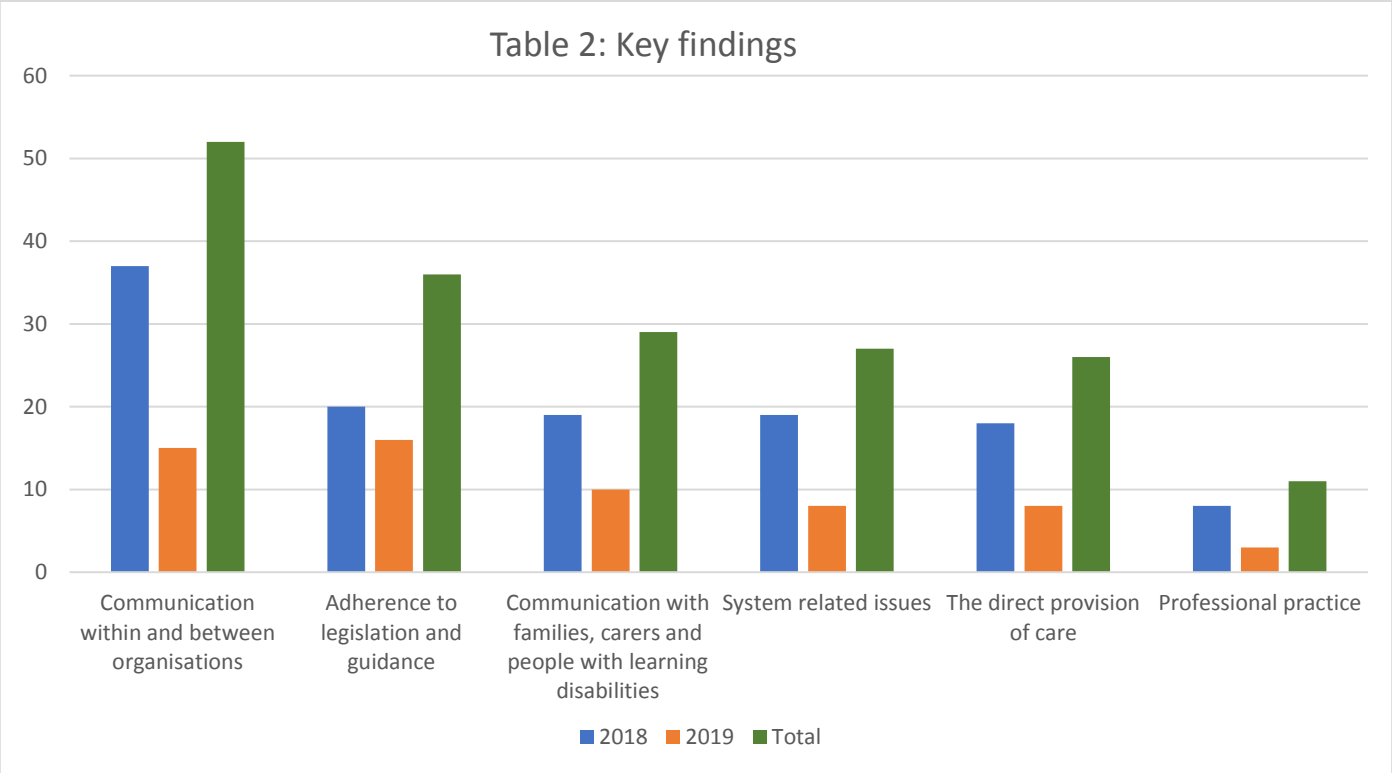
(1) KEY FINDINGS. These include examples of specific failings in the care of people with learning disabilities.

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

KEY FINDINGS

Key findings from the repository are related to failures in the provision of care and support provided to individual people with learning disabilities. These findings fall into six main themes:

1. Communication within and between organisations
2. Adherence to legislation and guidance
3. Communication with families, carers and people with learning disabilities
4. Systems related issues
5. The direct provision of care
6. Professional practice



1. Communication within and between organisations

The most frequent theme was communication within and between organisations (52 learning points). Within this theme the main issues are:

- A lack of multi-agency planning, coordination and communication.
- Agencies working in silos.
- Information and records were not shared between agencies.
- Timely action was not taken following assessment of needs.
- Risk went unrecognised because of a lack of joined up thinking.

Examples:

- *Jane's story is characterised by agencies working on parallel lines.*

- *There appears to be a communication failure between different teams.*
- *Risk assessments take place in silos.*
- *Support provider do not employ healthcare professionals as this is not part of their requirement as a supported living environment; Hospital assumed that Adult W was being discharging to a care home where an allied health professional would be available.*
- *Police did not know Charles had additional vulnerabilities or lived in supported accommodation.*
- *There are a number of documents held by a range of services that would benefit from a more streamlined comprehensive system.*
- *Two weeks before her death the Safeguarding Team recommended that multidisciplinary self-neglect pathways should be followed, but this was not implemented.*
- *At no point was a multiagency meeting held.*
- *Multiple attendances/admissions should have triggered a multi-disciplinary meeting/review.*

2. Adherence to legislation and guidance

Adherence to legislation and guidance was identified in 36 points. Within this theme the main issues are:

- A lack of implementation of the Mental Capacity Act.
- A lack of understanding of the Mental Capacity Act.
- People who knew the person best were not consulted.
- There were difficulties in applying the Mental Capacity Act to specific issues and understanding that a person may have capacity in one area but not another.
- Restrictive actions were taken without the appropriate assessments.
- An understanding of and training in relation to person centred care was lacking.
- Reasonable adjustments were not made.

Examples:

- *Her capacity was taken as a 'given' despite escalating service refusal and doubts about her capacity expressed by support workers who knew her well.*
- *There is evidence that the agencies considered Andrew's mental capacity in relation to finance, accommodation and surgery although the hospital did not consult a relative/person close to Andrew where best practice would dictate they do.*
- *Clinicians do not always uphold the rights of vulnerable people in relation to Best Interests under the Mental Capacity Act or fulfil their own duty of care because they may not consult others.*
- staff were unsure how to respond to challenging situations and had no training in addressing individual needs

3. Communication with families, carers and people with learning disabilities

Communication with families, carers and people with learning disabilities was found in 29 points. Within this theme the main issues are:

- Families were not invited to meetings where their input would have been valuable and necessary.
- Family involvement/the extent of family involvement in decision making was not questioned when it should have been.
- Diagnostic overshadowing affected the way professionals communicated with people with learning disabilities.

Examples:

- *Family were not invited to a professional meeting the month before Raymond died.*
- *The Care Plan did not take into account fully the concerns of both family and Care Provider.*
- *The transition process for children into adulthood was not as robust as it could be, both from J's perspective, but also in helping the family to understand the potential adjustments that they would need to be aware of when a child becomes an adult*
- *Stereotyping of people with a learning disability by a lack of poor communication, understanding of mental capacity and hidden attitudes affecting the way that professionals dealt with Mr D.*

4. Systems related issues

Systems issues were noted in 27 points. Within this theme the main issues are:

- Care plans and risk assessments were not evidenced.
- Appropriate checks were not carried out by commissioners.
- Staff training was not monitored.

Examples:

- *How training is monitored for its effectiveness in practice, with particular reference to the MCA, safeguarding and communication skills were not sufficiently documented.*
- Commissioning did not ensure that the Independent Provider established the necessary conditions to support Cassie

5. The direct provision of care

The direct provision of care was referred to in 26 points. Within this theme the main issues are:

- Care plans were not followed.
- Numbers of staff were inadequate.
- Staff were not appropriately trained.
- Evidence of diagnostic overshadowing where the person's learning disabilities or behaviours overshadowed the health issue.

Examples:

- *A significant number of practitioners are unaware that people with a learning disability have a higher incidence of bowel complications.*
- *None of the residential staff held qualifications in relation to this area of work.*

- *Provider/registered manager struggled with the management of the whole service; there was a lack of insight as to how to improve the service.*
- *Until the months before Cassie's HIV diagnosis, her tearful distress was seen as behavioural rather than as an undetected health problem*

6. Professional practice

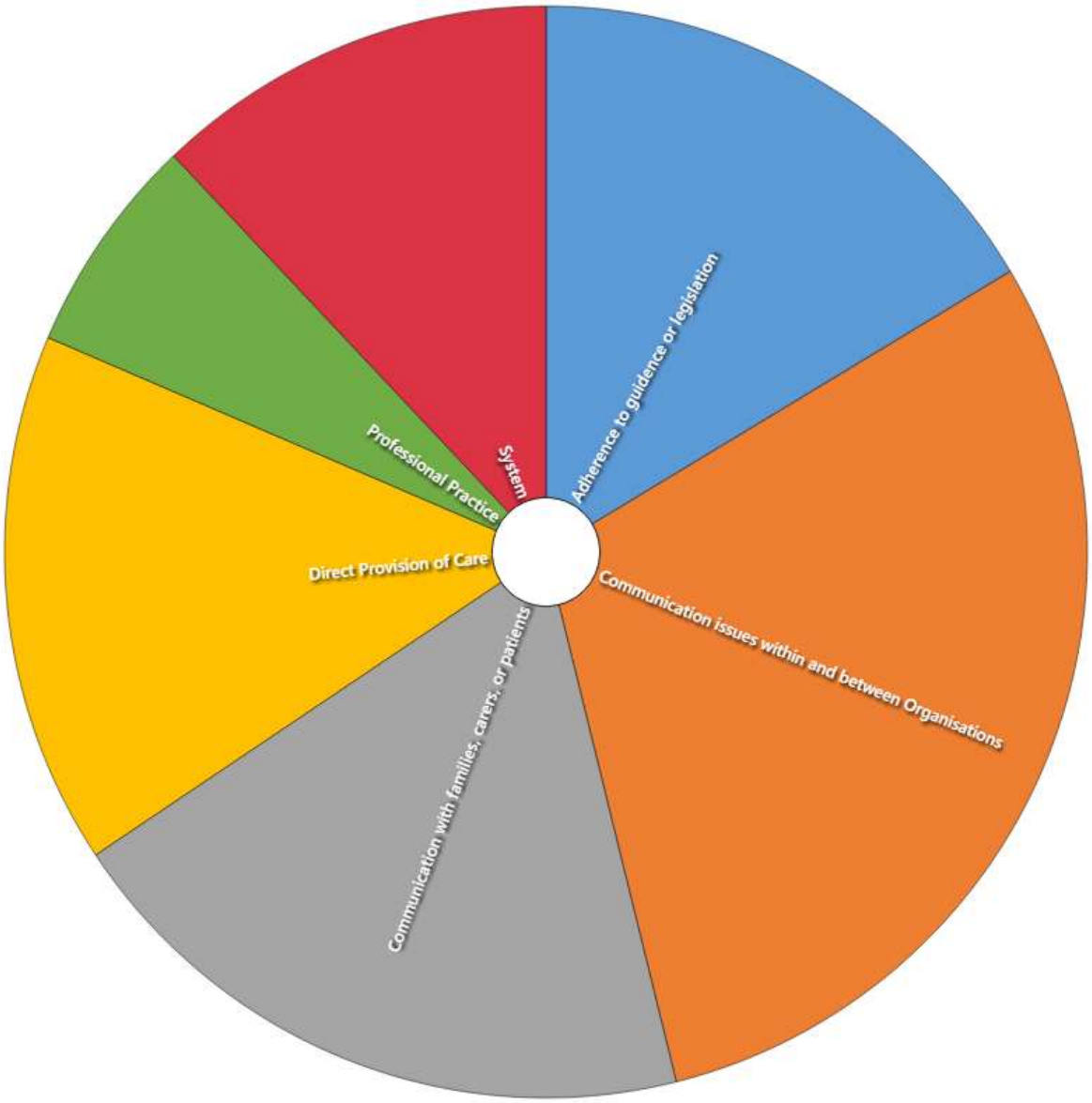
Professional practice was identified in 11 points. Within this theme the main issues are:

- Reports and records lacked appropriate detail.
- Workplace culture was unprofessional.
- Poor staff management.

Examples:

- *The prompt identification of the safeguarding concerns by staff in the Emergency Department, which led to the consultation with the Trust Safeguarding Team and notification, was good practice; However, both forms lacked detailed information and there is no explanation of the 'safeguarding concerns'.*
- *Days were organised around how certain members of the staff team wish to spend their time.*
- *The Deputy Home Manager should be far more proactive in their supervision and oversight of the staff team.*
- *There are concerns about staff recruitment, incident reporting, decision-making, disciplinary procedures and the attitude of the senior management.*

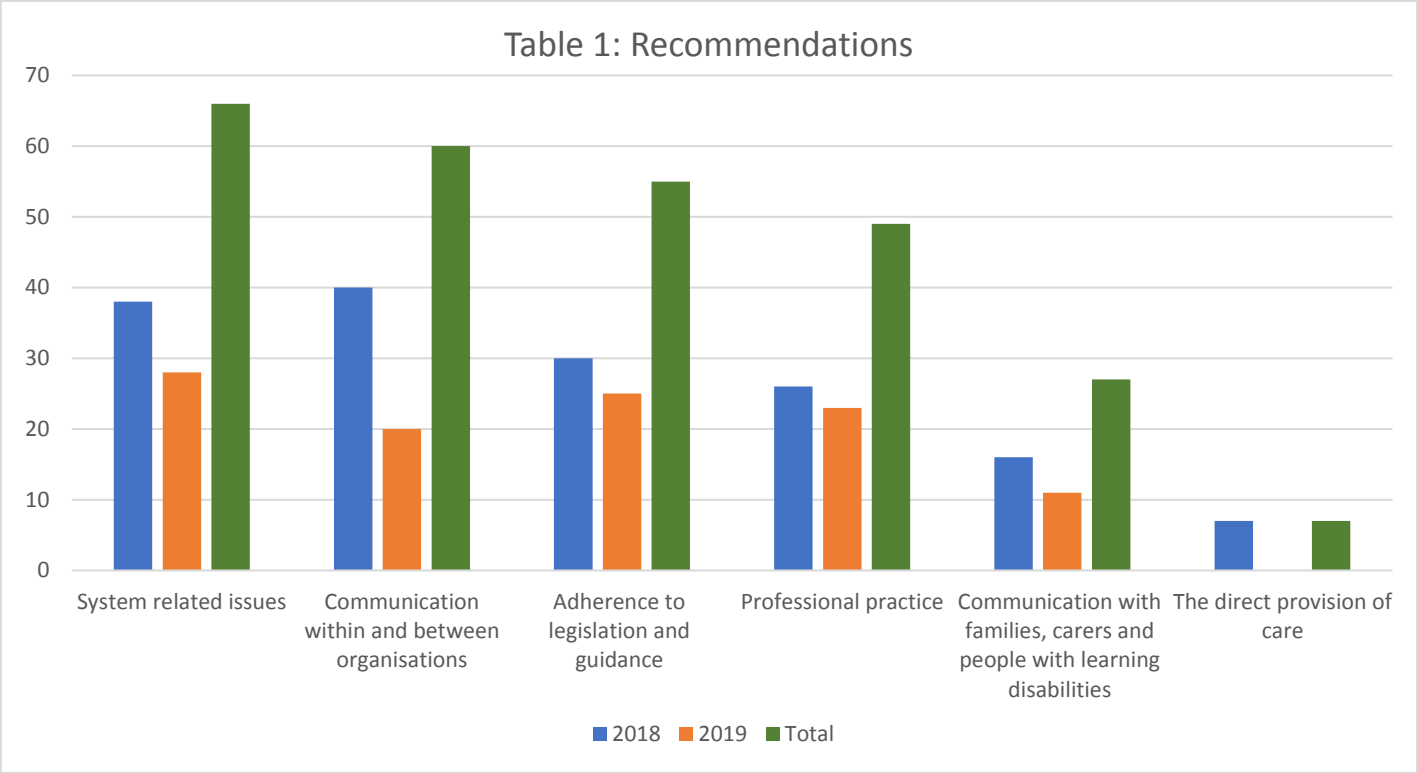
Key Findings



RECOMMENDATIONS

The recommendations from the reviews in the repository fall into six different themes:

1. Systems related issues
2. Interagency communication and working
3. Adherence to legislation and guidance
4. The direct provision of care
5. The need for training & professional practice
6. Communication with non-professionals



1. System related issues

The most frequent recommendation made was in relation to systems issues (66 recommendations). This included recommendations related to the introduction, change, or improvement of processes and practices.

Recommendations suggested:

- Personalised care plans should be embedded systematically – people with learning disabilities' specific conditions and needs must be understood and considered by all agencies involved.
- Information sharing should be assured across primary and secondary care. Mechanisms for this include the use of hospital passports and learning disabilities being flagged on medical records.
- Standards of care should be systematically monitored, and any failings addressed in a timely and appropriate manner.

- Multi-agency working to include all agencies involved, including those outside of the health and social care sector. The appropriate agency should take the lead and provide support for people with learning disabilities – i.e. if a crime has taken place, the police should take the lead and provide necessary support.
- Guidance required regarding which agency is to take the lead in relation to primary care access needs.
- Practice guidance regarding transition processes should be developed. Information and guidance should be made available and accessible for the person transitioning, families, carers, and professionals. This may be in relation to transitioning between service providers, or from children to adult services.
- The extent of family involvement should be understood across agencies involved – and understanding by these agencies of the role of particular families and carers in the lives and decisions.
- Placing authorities to ensure the provider has this suitably skilled team.
- Review of the Multi-Agency Hospital Discharge Policy to ensure that it sets out best practice in making safe and effective arrangements for people with complex needs.
- Review out of area care home placement reviews and monitor the frequency and timeliness of these.
- Policies and procedures for triaging safeguarding concerns should be reviewed, enhanced, and escalation policies made clear.

Examples of recommendations from the repository:

- *Commissioners must set out their plans for assessing the quality of provision in the local area.*
- *Care providers must ensure that they have communication plans in place which ensure that information sharing with other agencies is easily accessible and person centred.*
- *Use of Hospital Passports should be promoted and supported by primary care as well as secondary services.*
- *SAB should assure itself that…Social Workers are provided with appropriate training and risk assessment management tools used in responding to safeguarding concerns.*
- *Develop an information sheet for families to be provided when their relative moves into a care or supported accommodation setting.*

2. Communication within and between organisations

The need for improved communication within and across organisations was identified in 60 recommendations. This included planning multi-agency meetings, being able to have difficult conversations with colleagues, and the need for a lead worker/agency for coordinating multi-agency care.

Recommendations suggested:

- Supervision of case load should include potential for oversight to challenge as well as support the professional in their work. Individual workers should also be encouraged to show 'professional curiosity'.
- Guidance should be available within agencies for ways in which to convene multi-agency meetings – to include other agencies such as education, housing, probation services where necessary.
- Learning disability nurses were used more often.
- Multi-agency working that is taking place should be monitored within agencies, a lead agency appointed, and a designated key worker to take the lead.
- A culture of collaboration should be encouraged across agencies.
- Support workers familiar to the individual should be valued and utilised across agencies, with additional support for this where required.

Examples of recommendations from the repository:

- *Supervision practice should emphasise frequency and degree to which oversight of a case is challenging as well as supportive.*
- *Greater use should be made of the Learning Disability Nurse role.*
- *There is a named professional responsible for the effective co-ordination and review of the care arrangements.*
- *Local authority, CCG and hospital should explore providing additional support from support workers familiar to the person for people with substantial difficulties when in hospital.*
- *SAB should review current practice to ensure multi-agency meetings are held to share information and develop risk management plans.*
- *Safeguarding Childrens Board (SCB) should monitors its partner agencies' implementation of the Mental Capacity Act 2005.*
- *Should a patient who is receipt of community care be admitted to hospital, there should be effective communication between the hospital and both the home care provider and patient's family.*
- *Improve the planning and reviewing process between social care and health, in particular closer working with general practitioners.*
- *Where multiple agencies are involved with an adult with care and support needs, a lead agency should be identified.*
- *Care Quality Commission should be proactive in making connections with other settings managed by the same provider in order to satisfy themselves that these failings are specific to one setting and not occurring across the whole organisation.*
- *SAB should review current practice to ensure multi-agency meetings are held to share information and develop risk management plans.*

3. Adherence to legislation and guidance

Adherence to current legislation and guidance was identified in 55 recommendations. These recommendations included implementation of the Mental Capacity Act, advocacy and personalisation related points, and disability discrimination.

Recommendations suggested:

- There should be support for both people with learning disabilities, their families, and carers to express their views.
- The services of an IMCA should be employed when required. Staff should be trained to identify when this may be the case.
- The people who know the person best should be consulted where a person lacks capacity.
- Guidance required in relation to including views of family.
- Where compliance to guidance is found lacking, investigations should follow.
- Mental capacity act training to be carried out where necessary.

Examples of recommendations from the repository:

- *Staff supporting people with a learning disability have clear policies, procedures and support to escalate concerns where the mental capacity framework is not being followed.*
- *Commissioners and service providers should evidence that staff are able to apply the statutory requirements of the Mental Capacity Act in practice.*
- *All agencies should continue to work towards improving understanding the Mental Capacity Act and Deprivation of Liberty Safeguard.*
- *Practitioners need the confidence and support to establish capacity when it is unclear or fluctuating.*
- *Guidance to be issued to practitioners on the differences between learning disability and learning difficulties and the relevance for safeguarding judgments and services.*
- *Funding responsibilities need to be clear in order to avoid delays in services in compliance with the Care Act 2014.*
- *Staff must understand that the voice of a victim with learning disabilities needs to be heard by utilising the services an IMCA and appropriate interpreters, with a Mental Capacity Assessment completed by suitably trained staff.*
- *Review practice regarding the provision of advocacy for adults with complex physical health needs and learning disability.*

4. Professional practice

There were 49 recommendations in relation to professional practice. These were mainly in relation to training or guidance requirements. They also included points relating to recognising warning signs, record keeping, and cultural issues within organisations.

Recommendations suggested:

- Placing authority should ensure provider is sable to provide the services required.

- Ensure appropriate training on self-neglect is provided.
- Ensure professionals are trained in relation to carrying out good practice, identifying bad practice, and reporting on this bad practice when witnessed.
- Ensure staff are aware when to involve an outside agency for assistance.
- Meetings should be clearly documented, reviewed for accuracy, and shared.
- Professionals should be clear about when and how to report a safeguarding concern.

Examples of recommendations from the repository:

- *Develop across agency strategy to promote cultures which welcome and respond to complaints.*
- *A culture of openness and willingness to work with other agencies is required.*
- *Review district nursing and community matron services' approaches to working with people who self-neglect.*
- *Clarify what is adult safeguarding, what is poor practice or a "quality" concern; Specify the routes for concerns and the expectations of reporting on all agencies.*
- *Practitioners need the confidence and support to establish capacity when it is unclear or fluctuating.*
- *SAB should seek to challenge agencies that operate a "Did Not Attend policy". Agencies should consider renaming and operating the policy as "Was Not Brought".*
- *Magistrates to receive training in issues relating to Learning Disability.*
- *Staff who support people with a learning disability must be able to identify when an advocate is required and how to refer to one.*

7. Communication with families, carers and people with learning disabilities

There were 27 recommendations that referred to the need for improved communication with people with families, carers or patients.

Recommendations suggested:

- Development of information materials for families when their relative moves from the family home.
- Assess 111 procedures in relation to patients who have communication difficulties/additional needs.
- Support people to manage their budget and ensure carers are appropriately skilled where the individual with learning disabilities has assigned a non-professional to manage their budget.
- Ensure families can express concerns.

Examples of recommendation from the repository:

- *Develop an information sheet for families to be provided when their relative moves into a care or supported accommodation setting.*
- *GP's should consider the proactive use of special patient notes to NHS 111 for non-verbal patients, in the same way that patients who are approaching the end of life, to promote effective communication.*

- *The Transforming Learning Disability Services' initiative of the CCGs should be embedded in relation to the promotion of greater attention to individual support needs which credibly involves self-advocates and engagement with the families of people with complex support needs.*
- *Involve the individual and their family in safeguarding enquiries.*
- *Local authority, CCG and hospital should explore providing additional support from support workers familiar to the person for people with substantial difficulties when in hospital.*
- *Other practitioners who know the patient best should be consulted and their views recorded whenever possible.*
- *ASC should seek assurance that a Carers Assessment as per the Care Act 2014 is offered where it is apparent "Carers" require additional support.*

5. The direct provision of care

The direct provision of care for people with learning disabilities was identified in 7 recommendations. This was in relation to care plans, needs assessments, and diagnostic overshadowing.

Recommendations suggested:

- Staff should be accountable for poor care provision.
- There should be an evaluation of specialist care provision to ensure provision of appropriate services for particular conditions.
- Assumptions should not be made about a person's ability to communicate and appropriate assessment must take place in order to understand this.

Examples of recommendations from the repository:

- *No assumptions should be made about cognitive impairment and in safeguarding processes appropriate assessments always need to be considered.*
- *Paying particular attention to the challenge of "diagnostic overshadowing".*

Recommendations