

LeDeR Themes 20 – 21

Contents

Introduction	2
Cross-System Recommendations:	
1. Holistic approach to needs	2
2. MCA	2
3. Family	3
4. Reasonable Adjustments	3
Organisation Specific Recommendations:	
5. Social Care	4
• Planning	
• Training	
• Processes	
• Working with hospitals	
6. Primary Care	5
• Annual Health Checks	
• Pathways	
• Other issues	
7. ELDP	7
8. Acute Hospitals	7
Condition Specific Recommendations	
9. Frailty	8
10. Heart	9
11. Cancer	9
12. Dysphagia	10
13. Dental	11
14. End of Life	11
15. Learning into Action	12

Introduction

Of the 137 reviews completed to date, 318 recommendations were made. Themes have been grouped in order to enable organisations to identify actions, but colour coding has also been used to show **systemic** and **organisation** specific issues. Items which are specific only to individuals will be communicated through a copy of the review to the relevant organisations involved.

1. Holistic approach to needs

This theme covers not only **joined up working** across the health and social care sector and the need for a “**case management**” function, but a **broader approach** to the needs of people with LD, who typically struggle to access information and services which take into account their needs in the wider context.

“the link between XX managing his finances and becoming malnourished should have been identified, and something simple like instating Meals on Wheels considered”

“in reviewing XX's death, I am aware I have access to different accounts of his health, but during his life, no one person had the oversight available to me from hospital notes, GP records, social care and provider notes read in conjunction. A more joined up approach to care-co-ordination would greatly assist this”

“professionals involved with people with LD, should not only consider the areas in which they are particularly involved (finance, mental health, community support etc) but also be prepared to notice and act on changes to physical health.”

Action Points:

- Information sharing across all health and social care services
- A single functional and holistic plan agreed by the person with LD and their family across all health, social care and voluntary services
- A flexible case management function across health, social care and voluntary services
- Shared risk and escalation system
- Physical health pathways across all agencies, families and carers

2. MCA and Health Insight (42 recommendations)

In a number of cases, healthcare was refused and the person was deemed to have mental capacity to make this decision – in some cases leading directly to death. It was not clear that the person really understood the likely consequences of their decision and no work was evident to support that understanding.

The views and knowledge of families should always be taken into account, particularly in best interest decisions, but in some instances families made decisions to refuse healthcare outside their legal responsibility and when the mental capacity of the person was not clear.

An MCA Easy Read Toolkit and Specialist support is available to work through decision making, but early referrals are needed to allow time for this work to be done.

MCA should be considered for all major decisions – there is a need for broader training on this.

More information available to families, medical staff and care agencies about Lasting Powers of Attorney and deputyship to enable conversations about what is in a person's best interest and who can make decisions

Issues of self neglect should be raised as safeguarding alerts

All MCA and best interest processes and decisions should be clearly recorded in notes.

Actions

All organisation to review their training and process around MCA and people with Learning Disability

3. Family

Families need better information on what services and community resources are available to them.

A consistent contact to explain and help navigate health and social care, benefit and community services may be of benefit to help families with adult children with LD.

An assessment of a person's need should include the context of the family, especially if they live at home. The family hold vital information and insight into the person and are often their main carers.

A carers assessment should be carried out in this instance.

Some families are very reluctant to allow health or social care services into their lives and this means the person first comes into contact with services in crisis when very little can be done. Better engagement at transition into adulthood should keep contact with such families.

A number of adults with Learning Disabilities live with elderly parents, whose own health needs are significant. Earlier planning should be put in place to enable them to prepare for a time when they cannot be the main carers.

Families should be involved in decision making

Actions

All organisations to engage with family representatives and family focused organisations to review practises.

4. Reasonable Adjustments (13)

It is important that adjustments are made to the usual way services are offered so that people with Learning Disability can make use of them. Reasonable adjustments will be specific to each individual but common themes are:

- Availability of Easy Read Information
- Communication – use of sign, symbol, simple language, repetition and checking back.
- Availability of hearing aids, batteries and glasses
- Phobias and anxieties around transport or health venues

- Time – longer appointment times, early preparation and time for re-visiting information.

The ELDP Specialist LD Health service is available to advise and support the implementation of reasonable adjustments in the community and LD Hospital Liaison Nurses advise in acute settings.

Inclusive Communication Essex (ICE) produces and holds a list of Easy Read resources for Essex.

There are a range of resources on the internet to support reasonable adjustments and give Easy Read versions of common documents

Action:

[Communication is needed to promote the services and resources available](#)

Organisation Specific Recommendations

Having noted the need for the above and the fact that almost all recommendations involve more than one organisation working together, it may be helpful for action to identify the main organisation specified in the recommendation:

5. Social Care (103 recommendations)

This was the area with the highest number of recommendations and can be split into further areas:

Planning and getting the right support/place to live: When looking at both housing and social care support (either as a first placement or a move between providers) a better solution can be found if a range of information is taken into account. Families, current providers and Specialist Health (particularly for syndromes or long term conditions) often had information which was not included. In one case ignoring direct advice from a specialist Consultant lead to the death of the individual.

Issues of compatibility between tenants, more robust assessment of quality and location close to family and circles of support were also raised.

Action Points

- [Integrated holistic assessment](#)

Training: Social care providers are often the ones making a decision about calling the GP or ambulance, checking on a person's wellbeing, helping them plan food or access daily activities. These kind of contacts are key to wider wellbeing but despite demonstrating great care towards adults with Learning Disability, providers generally did not have the relevant training to recognise health issues, help the person understand relevant information, maintain their health or access health services. Key areas where this impacted on quality of life and life expectancy were:

- Healthy living – nutrition, hydration weight, smoking, exercise, bowel health, health screenings and annual health checks. How to access and explain information, how daily activities can support health, how to access relevant services in the community.
- Long term conditions – (respiratory, cardiac, diabetes, epilepsy, continence) helping the person with management of diet and exercise plans, identifying triggers to worsening

condition, recognising side effects and exacerbations and how to access support from specialist services

- Frailty – falls prevention, mobility, posture, skin integrity, recurrent infections, nutrition and hydration. How to access advice and relevant services to prevent deterioration.
- End of Life – see section below.

Social care providers cannot carry out these functions in isolation, but must be part of the wider team who collectively take responsibility for the overall care plan.

Action Points:

- Training for Social care providers (E.g. LD Significant Seven)
- Joined up health and social care commissioning
- Focused LD Public health programme supporting social care providers
- Clear LD frailty offer
- Directory of services

Also see section on MCA and Health Insight below

Processes and Systems

Without agreed and well understood processes, practise is inconsistent and dependent on local context and the knowledge of individuals. The areas highlighted as needing action are as follows:

- Handover of information between providers should be systematised as key issues have often been lost on move of home.
- Community Mapping should be used by providers to understand and manage how daily activities contribute to wellbeing
- Falls risk assessment should be in place and re-assessed on move of home
- Awareness and use of specialist LD health services should be improved
- Flagging of people with phobias and anxieties, particularly around health, transport, needle-stick etc should be in place with a clear pathway to de-sensitisation services.
- Clear routes for communication between providers and ASC/Health should be in place for significant changes/escalations in health.

Working with Hospitals

Hospital passports should be up to date and with the person on conveyance to acute setting and should include information on relevant phobias/anxieties

A familiar person should be with the person when they are admitted to hospital

Good channels of communication between hospital, the social care provider, social care should be in place to

- a) Ensure appropriate and timely admissions
- b) Ensure safe and appropriate discharge

Clear information on the type and availability of social care support should be clear in the discharge planning

Clear information on the person's needs and relevant actions for social care providers should be clear in the discharge plan

Families – see section above.

There were also 11 recommendations specific to individual cases, which will be shared with social care.

6. Primary Care (69 recommendations)

Annual Health Checks (32):

GPs have an opportunity in the Annual Health Check to gain an overview of the person's wellbeing, but in many of the reviews the check was not offered, did not highlight relevant issues or did not result in a Health Action Plan.

“GP's should be reminded that even where a person with Learning Disabilities is under an acute specialist service for management of a serious medical condition an AHC is still required and healthy lifestyle messages that may impact on their medical condition, should be reinforced at the AHC. These appointments should be regarded as an opportunity to explore the wider health issues for the person with LD and their carers.”

GPs often seemed unaware that there are specialist services who can support a person with preparation for health check, anxieties around health appointments and can be referred to for direct treatment.

Easy Read materials are available on CCG websites to promote and support AHCs

Action Points:

- System for flagging those who do not attend AHCs
- Use of social prescribing allied to AHCs
- Use of Easy Read materials to invite people to AHCs and help them prepare
- Inclusion of key issues in AHC: healthy living, medication, oral hygiene, falls and frailty risks, dementia scores
- The person's ability to not only understand at the time, but to retain and implement advice should be taken into account when agreeing an action plan and the need for support should be reflected in it and communicated to the relevant people.
- Health Action Plans to be agreed and shared with the person, family and all relevant people across health and social care.

Pathways (12)

There is a need for training for Primary Care staff to adjust their communication other ways of working to enable a clear understanding of the person with LD and their health. People with LD often cannot articulate their symptoms and assumptions are made. Behaviour (which may indicate pain), weight loss or gain, a change in mood or habits can all indicate an underlying health need. Physical causes should be ruled out and family or carer information should be carefully considered.

There are a range of services to support people with LD and to work alongside primary care, but awareness and use of them is inconsistent. Pathways need to be agreed and widely understood:

There should be clear and agreed pathways in place when symptoms or conditions present to primary care, which ensure the correct services are involved and coordinated. (Dysphagia, Epilepsy, Dementia, Pierre Robin Syndrome, phobias and anxiety around health

issues, significant weight loss or gain, frailty, side effects of specific drugs for epilepsy and gastric conditions, End of Life).

Families and social care providers need to be included in these pathways to ensure they understand symptoms to look out for and when to call in the appropriate help.

Best interest meetings could be part of these pathways (see also section on MCA below)

Medication reviews should be held regularly, but also triggered when symptoms are reported that could be side effects of medication. (see also integrated STOMP Pathway)

There should be clear criteria for home visits

Action Points:

- [Pathway development](#)
- [Training on reasonable adjustments](#)

Other Issues for Primary Care (25):

preparation for an uptake of health screenings is low for people with Learning Disability and there needs to be a drive to provide accessible information and help a person make informed decisions and prepare for a screen.

Reasonable adjustments are key to supporting good health

Other items relevant to specific cases to be shared with PCNs.

7. Specialist Health (ELDP) 11

Most recommendations indicated the need for specialist LD services to be involved in a person's care and to be referred to in a more systematic way.

Services should be involved in specific condition and inter-agency processes such as discharge.

GPs and social care workers and providers are often unaware of what is available or how to access.

See also section on dysphagia

Action Points:

- [Description and wide communication of services available and how to access them](#)
- [Involvement in multi-agency pathways](#)

8. Acute hospitals

Admissions – information should be available on the communication needs, underlying health condition, reasonable adjustments necessary, This should be captured in an up to date hospital passport and a “blue bag” should come with the person, but family and carers should be in attendance to explain and handover.

A familiar person – family or carer should be available to the person while in hospital

Advocacy should be routinely available to people with LD, but especially where they have no family or carer.

The role of the **LD Hospital Liaison nurse** was very positive and should be available 24/7 with increased staffing.

DNACPR – the process was generally well followed but sometimes assumptions were made about the person’s “Quality of Life” where there was little information on the person’s quality of life prior to admission. Family members, while consulted sometimes reported feeling directed by medical staff and not having sufficient time or information on which to make a decision.

Communication with community - clear pathways to community services should be agreed to

- a) prevent the need for admission,
- b) optimise hospital stays (by de-sensitisation programmes, sharing of information and preparation work) and
- c) enable a successful return to health at home after discharge

Discharge –checks should be made to ensure that prescriptions can be accessed, equipment is in place and that the home environment is suitable for discharge, particularly where elderly parents are the carers.

An integrated plan with community services is needed on discharge

Clear plans outlining the role of community services and the family/carers responsibility should be made available to families and carers on discharge – this should include what symptoms to look out for and when to ask for further intervention.

There should be a system to identify people who return to hospital, especially with the same condition. Their care and support in the community should be reviewed and addressed to manage their health and wellbeing.

Better communication is needed between specialist centres and local acute settings to ensure coordination of care.

End of Life – see below

Action Points:

- **Review of hospital passports and blue bag**
- **Integrated pathways with community services**
- **Integrated and accessible Discharge plan**
- **Accessible information for people with LD and their families/carers**

Condition specific Recommendations

9. **Frailty**– despite the highest cause of death being pneumonia, most of the recommendations relate to social care providers not recognising or acting to prevent deterioration, which ends in pneumonia or sepsis. This fits into a wider picture of early frailty, as described in last year’s report. This is typically not recognised in people with LD who do not fit the age criteria and do not have anyone to coordinate their care.

There is a need to work collaboratively across health and social care to ensure the following for people with LD

- a) Prevent falls
- b) Maintain mobility and posture
- c) Maintain good nutrition and hydration
- d) Manage long term conditions
- e) Identify signs of frailty and mitigate deterioration
- f) Identify signs of crisis and act quickly to get help

Constipation – people have died from gastric and bowel related conditions involving long term constipation. Obstruction of the bowel and side effects of long term laxative use are not uncommon. Exercise and diet are almost never recorded to manage bowel health. Dieticians are rarely referred to for management of bowel health.

Action Points:

- Communication plan to raise awareness of bowel health and how to manage it

10. Heart

As well as being a direct cause of death, cardiac issues came up frequently in 1b, 1c of death certificates. Reviews did not find corresponding concern around heart health or understanding of the role of healthy living in maintaining heart health in families or social care providers and there is a large public health piece of work to improve this.

Recommendations largely relate to management of known or queried cardiac conditions:

- The Specialist Cardiac Nurses need to ensure when a patient has a Learning Disability that both patient, family and Care Home staff are informed about the national charity 'Cardiomyopathy UK' which have a website and helpline to support patients and their carers to help them have a fuller understanding of the heart condition.
- Easy Read materials relating to Cardiomyopathy/Heart Failure need to be developed and provided to patients with Learning Disabilities and their carers when they attend their Outpatient Appointment with the Consultant Cardiologist or Specialist Cardiac Nurses. The hospital LD Liaison Nurse should support this development.
- All Cardiac Specialist medical staff (medics and nurses) need to be made aware of the role of the LD hospital based nurse and how they may support those patients and their carers attending their clinics. Referrals should be always be made.
- Adults with Learning Disability who have a history of congenital heart disease such as Fallot's Tetralogy & repair should be routinely referred into the local Cardiology Clinic for regular monitoring to ensure any heart failure symptoms are identified early so treatment options can be explored and implemented in a timely way, whether this be active treatment or palliative care. This should be included as part of the Annual Health Care Plan developed following the GP Annual Health Check.
- Health Care Plans for those who have an increased risk for potential heart disease need to include the management of wider health determinants such as diet, fluid intake and exercise. Health Care Plans should be regularly reviewed at the Annual Health Check and desired outcomes monitored to ensure the interventions are effective.
- DNAs (E.g. for cardiac appt) should be escalated

Action:

CCGs to follow up recommendations with primary care and specialist cardiac services.

11. Cancer

- People with LD are suffering from bowel cancer at an earlier age when they have a learning disability. May be the NHS bowel screening programme age could be lowered.
- Oncology Department should ensure those with Learning Difficulties and their carers are made aware of easy read materials which explain what happens at review Out Patient Appointments including examinations and investigations.
The Macmillan website has a range of appropriate materials that can be downloaded.
<https://www.macmillan.org.uk/information-and-support/resources-and-publications/other-formats/easy-read.html> and <https://be.macmillan.org.uk/be/p-23308-scans-and-x-rays.asp>. Patients could be sent details of the website link in their OPA appointment letter.
- The transfer of records between out of area Oncology services in acute providers needs to be reviewed to ensure timely sharing of information about treatments follows the client. Where the patient has identified Learning Difficulties the LD liaison nurse in the receiving area should be notified.
- Long term treatment for DVT should follow the most up to date NICE Guidance on management of DVT - this includes assessment for undiagnosed cancer and checking compliance with medication.
- Training for Primary Care Staff could include early recognition of blood cancers.
- GP Practices should ensure that those who have Learning Disabilities have Easy Read versions of the Bowel Cancer Screening test instructions that they can utilise and ensure where those with LD decline to take part in the screening programme (GPs receive notification of outcomes) that this is followed up and addressed at the next Annual Health Check.
- Where there are concerns about Capacity to consent for cancer screening programmes an MCA should be undertaken the result recorded and where appropriate a Best Interest Decision made as to whether to exclude the individual from the programme.

Action:

CCGs to follow up recommendations with Primary Care and oncology services

12. Dysphagia

Aspiration pneumonia is a common cause of death locally, often despite recommendations for textured diets being in place. Food and eating is very emotive and people with LD and their carers don't always fully understand the risks – in one case with a well meaning carer feeding a person cake when they could not safely swallow.

Advice on textured diets does not always transfer between care providers, day centres and there can sometimes be confusion when advice changes after a stay in acute.

PEG feeds often got blocked and management was not well understood.

Action Points

- Training for families and social care providers on textured diets and PEG feeding
- Clear agreed plans with risks of non compliance clearly set out and communicated to all involved.
- System for monitoring textured diet status between acute and community – hospital passports can support this.

13. Dental

Poor oral health was a contributory factor in a number of reviews, but issues prevented access to dentistry, typically phobias, uncontrolled diabetes or difficulty with General Anaesthetic .

Poor oral hygiene was also common

Specialist dental services and de-sensitisation programmes are available but not widely accessed

Action Points:

- De-sensitisation programmes to be advertised more widely
- Training and key messages around oral hygiene to be provided widely and for all ages
- Joined up planning to be in place where multiple factors prevent oral health

Other

- **NICE Guidance on reasonable adjustment in Diabetes care for people with LD should be followed consistently**
- **Epilepsy registers should be reviewed and validated**

14. End of Life (49)

End of Life planning occurs too late and is therefore rarely inclusive of the person's wishes. No one identifies the deterioration in health which will eventually lead to death (even where this is feasible) and so time is lost to maximise the person's quality of life and help them explore their health and end of life options. This is usually too early for hospice involvement, but no one agency identifies this as their role. **An integrated approach is necessary**

Some social care providers have delivered excellent end of life care in conjunction with health services, but others have not the skills or confidence. An audit, with targeted training and peer support could improve consistency.

It may be necessary to involve the palliative care team earlier than usual to enable time for planning and exploration of wishes

Advocacy can be very helpful in this work

Action Points:

- A clear agreed inter-agency "dying well" approach and pathways, based on co-development with people with LD.
- Training and accreditation for social care providers in End of Life care
- Materials for End of Life planning with person and family
- Early involvement of palliative services

Learning into Action

All themes will be followed up through presentations to the Steering Group and review of the action plan.

Organisations will take responsibility for implementation of recommendations relevant to their own organisations and for making links with other agencies within their own footprint.

LeDeR LAC is available to support and facilitate integrated pieces of work where this is necessary.

It is suggested that four priorities are taken forward for an integrated approach to end March 2021:

- Annual Health Checks
- Frailty
- Dynamic Support Register
- Case Management

Rebekah Bailie
LeDeR Local Area Coordinator
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