NHS
Leicester City Clinical Commissioning Group
West Leicestershire Clinical Commissioning Group
East Leicestershire and Rutland Clinical Commissioning Group

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University Hospitals of Leicester
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Leicester City Council

NHS
Leicestershire Partnership
NHS Trust

Leicestershire County Council

Leicester, Leicestershire and Rutland LeDeR Annual Report

June 2020

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Foreword

We must do more to ensure that people with a learning disability do not experience health inequality. There has been no clearer reminder of this than the awful abuse exposed at Whorlton Hall Hospital in County Durham.[1]

This is why the LeDeR programme is so important. It represents a real opportunity to improve the lives of people with learning disabilities. Implementation in Leicester, Leicestershire and Rutland has been difficult, but much progress has been made. It means that we are now in a position to make evidence-based recommendations as to how the quality of health and social care services for people with learning disabilities can be improved.

There are two sets of people that deserve special recognition. The first are our LeDeR reviewers. Without their expertise, experience and passion we would not be where we are. The second are the families, friends, carers and health and social care professionals who have provided critical contributions to each LeDeR review. Their support has been invaluable.

We must not rest upon the contents of this report. Instead all partners across the Leicester, Leicestershire and Rutland health and social care sector must embrace the initial findings of this report' everyone has a role to play. Only then will we ensure that every person with a learning disability receives the high quality of care that they deserve. Only then will we address health inequality.

Caroline Trevithick, Chief Nurse & Executive Director, West Leicestershire CCG
Peter Davis, Assistant Director (Adults & Communities), Leicestershire County Council
David Williams, Director of Strategy and Business Development, Leicestershire Partnership NHS Trust

60	The average number of learning disability deaths across LLR referred to the LeDeR programme per year since October 2017.

[1] https://www.bbc.co.uk/news/health-48367071

1. Executive Summary

1.1 This is the first Leicester, Leicestershire and Rutland Learning Disability Mortality Review (LeDeR) Annual Report. Unless stated otherwise it covers the period October 1st 2017 – March 31st 2020.

1.2 **The median age of death for people with a learning disability in Leicester, Leicestershire and Rutland (LLR) is 59 years old.** According to the most recent England LeDeR Annual Report this is 23 years younger than the national median for men; 27 for women. The LeDeR programme aims to address this health inequality.

1.3 Since LeDeR was launched in LLR on October 1st 2017, health and social care partners have been working hard to ensure its successful implementation. Much progress has been made, especially in the last 12 months. **This means the question can turn from 'how can we implement LeDeR in LLR?' to 'how can we use LeDeR to improve the lives of people with a learning disability?'**

1.4 The LLR LeDeR programme has identified many examples of excellent person-centred care. However, it has also highlighted several areas where improvements are required. Most of these improvements fall under the broad themes of:

- Advanced Care Planning and End of Life Care
- Communication & care coordination
- The application of the Mental Capacity Act and Best Interest decision making
- Diagnostic overshadowing
- The role of carers in diagnosis and case management

1.5 How the local health and social care system can replicate good - and address poor - practices will be covered in an additional LLR LeDeR Report published within the next 12 months. This is called 'Learning into Action'.

1.6 Significant and sustained system-wide change can only be achieved through collaboration. **The LLR LeDeR Steering Group therefore not only thanks partners for their help in delivering the programme to date, but also challenges them to implement the improvements needed to address the health inequalities that people with a learning disability face.**

1.7 Sadly, over the past few months several people with a learning disability in LLR have died because of the COVID-19 global pandemic. These deaths do not fall into the remit of this report. That being said, the LLR LeDeR Steering Group want to assure partners and the public that any learnings from these deaths are being addressed at pace through the system's COVID-19 response. This is achieved through a COVID-19 specific 'rapid response' LeDeR Review. At time of writing every COVID-19 death that has been referred to the LeDeR programme has been reviewed through this approach.

59	Median age of death for people with a learning disability in LLR. This is the same as the national median, but not what we aspire to. Our aim is to reduce the mortality gap for all people with a learning disability in LLR.

10%	A person with a learning disability is 10% more likely than those without to be admitted to a hospital ward from the Emergency Department.

2. Introduction to the LeDeR programme

2.1 The aims of the LeDeR programme are:

- To support improvements in the quality of health and social care service delivery for people with learning disabilities

- To help reduce premature mortality and health inequalities for people with learning disabilities

The programme is funded by NHS England but delivered through local partnerships like LLR.

2.2 The LeDeR process is summarised below:

1. Anyone with a diagnosed learning disability who has died over the age of 4 years old since October 1st 2017 can and should be referred to the programme. The more people who are referred the stronger an evidence base for change can be developed.

2. Each LeDeR referral is allocated to a local LeDeR Reviewer. In LLR these are trained health and social care professionals experienced in working with people with learning disabilities. As much as possible LeDeR Reviewers are not asked to review care for individuals in which their 'home' organisation was a substantial part of service delivery. This is not always possible. However, the LeDeR Steering Group is assured that where this is the case, Reviewers are impartial in their consideration.

3. The purpose of the 'Initial Review' is to identify key learnings and recommendations to improve local health and social care services. To do this the LeDeR Reviewer will consider relevant case records and speak to family, friends and carers to form a 'pen portrait' of the individual and coherent narrative of their care in the lead up to their death.

4. Where there were significant concerns about the person's health and social care service delivery further information can be gathered through a Multi-Agency Review (MAR).

5. Before each Initial Review is approved it undergoes a quality assurance process. LLR has set high standards that every Review must meet.

6. Learnings and recommendations from every completed LeDeR Review is fed into national and local 'Learning into Action'.

7. Deaths for children with a learning disability are reviewed as part of the Child Death Overview Panel (CDOP) process. In LLR this is achieved through 'themed' panels where the exclusive focus is on learning disability deaths. The learnings and recommendations are then fed into LLR LeDeR 'Learning into Action'.

2.3 Each LeDeR Steering Group is required to publish an Annual Report; this is the first for LLR. This is supplemented by a national LeDeR Report. Each report typically includes:

- Progress to date in the allocation and completion of local LeDeR Reviews.
- Learnings and recommendations that have been identified.
- How these form 'Learning into Action'.

This report will focus on the first of these; the other two only touched on in brief. Instead they will be the focus of a further 'Learning into Action' report published within the next 12 months.

3. LLR statement of Purpose

3.1 The LLR Learning Disability and Autism Partnership are committed to the ongoing delivery of the LeDeR Programme. This means:

1. That LeDeR Reviews are allocated and completed to a high standard within the stipulated programme timescales.

2. That identified learnings and recommendations become 'Learning into Action'.

3. That 'Learning into Action' improves the quality of health and social care services and reduces the health inequality faced by people with learning disabilities.

4. That all stakeholders, including people with learning disabilities and their family, friends and carers, feel an equal partner in the LeDeR programme.

These ambitions sit within the broader LLR system-wide Person-Centred Leadership Framework.

'His care was just perfect for him, it was a lovely home. They were really caring people and it really made a difference to him and his life. That's important for family to be able to walk away knowing he was safe and happy. This was the third care home he'd been in since 2000 but it was the best of all, we would leave knowing we had left him happy in his real home. If ever he went into hospital the staff would choose to stay with him so he wasn't frightened, they would just forget their shift had ended. We miss him a lot and we are glad he was so happy in the last years of his life'.

Feedback from a family member included in a LLR LeDeR Review. This is the kind of care and support that all people with a learning disability in LLR should receive.

4. How the programme is delivered in LLR

4.1 The day to day management of the LeDeR Programme is undertaken by the three Local Area Contacts (LACs). Each focuses on a different aspect of the programme: administration, clinical quality, and performance and business intelligence. Further support is provided by a locally funded Clinical Quality Lead who is responsible for ensuring the quality and speed of local LeDeR Reviews. Alongside the Steering Group Chair this forms the LLR LeDeR Leadership Team.

4.2 The LLR LeDeR Programme is overseen by a Steering Group. Each LLR local authority, Clinical Commissioning Group (CCG) and NHS Trust is a member. It is chaired by Leicester City CCG's Deputy Director of Nursing and Quality. The ambition is to expand membership so that other key stakeholders, including people with a learning disability, are represented.

4.3 The LLR LeDeR Steering Group provides periodic updates to LLR Learning Disability & Autism Executive Board, LLR Safeguarding Boards and other stakeholders. This includes reporting on behalf of local CCGs to NHSE/I.

4.4 Lastly, during the next 12 months the LeDeR Steering Group will be prioritising engaging with people with learning disabilities, their families, carers and wider communities. This includes ensuring we meet our responsibilities under the Equalities Act to consider the views of different age groups, cultures and other socio-demographics. This is the basis by which we will integrate people with a learning disability into the LeDeR programme, whether directly or indirectly through established voluntary, community and faith organisations.

17% Of LLR LeDeR referrals are for people who are BAME. This is above the national position (which is 10%), but lower than would be expected for LLR. Engagement with BAME people with a learning disability, their family, carers and those who represent them is the foundation by which the LLR LeDeR programme will address this disparity.

5. Indicative learnings & our initial response

5.1 This Annual Report will be supplemented within the next 12 months by another dedicated to 'Learning into Action'. However, evidence gathered from completed LLR LeDeR Reviews to date provide some initial learnings and an early indication of what the priority areas of focus will be to improve the lives of people with learning disabilities. These learnings have been separated into those informed by qualitative and quantitative evidence.

Quantitative

5.2 15% of people with a learning disability were prescribed anti-psychotic medication with no recorded attempt of a withdrawal; 18% anti-depressant medication with no recorded attempt. This is critical evidence to feed into the LLR 'Stop the Over Medication of People with a learning disability, autism or both' (STOMP) and 'Support Treatment and Appropriate Medication in Paediatrics' (STAMP) programmes.

5.3 At least 21% of people with a learning disability did not have a recorded annual health check during the last year of their life. Leicester City CCG will be presenting findings from a review conducted last year into the quality of annual health checks to the LeDeR Steering Group. Working together the objective is to ensure that all people with a learning disability have a high-quality health check each year.

5.4 91% of people with a learning disability had a Do Not Resuscitate Order (DNACPR) in place when they died. The LeDeR Steering Group and other stakeholders must be assured that DNACPRs are applied appropriately. It is intolerable that any DNACPR is put in place for a person where having a 'learning disability' is the stated justification.

5.5 12% of those DNACPRs were either not followed or completed correctly. The LeDeR Steering Group, through our approach to 'Learning into Action' will feedback to any organisation where this poor and dangerous practice has been identified.

Qualitative

5.6 The first theme is Advanced Care Planning & End of Life Care. This means:

- The consistent application of Advanced Care Planning where it is needed, regardless of the care setting.
- Ensuring that GPs, Primary Care and Hospital teams use RESPECT forms.
- Promoting the use of Palliative Care Teams to help recognise people who are deteriorating and may need End of Life Care.

5.7 The second theme is communication and care coordination. This means:

- Improving communication and the role that it plays in diagnosis and case management across all health and social care services.

- The implementation of an electronic referral system in UHL to refer patients with a learning disability to the Acute Liaison Team.

- Information sharing between partners to ensure that reasonable adjustments are being applied regardless of the care setting.

- Care co-ordination for all children with a learning disability with complex care needs is led by a named lead clinician.

5.8 The third theme is the Application of the Mental Capacity Act and Best Interest decision making. This means:

- Training all clinicians so that they have a good understanding of their responsibilities under the Mental Capacity Act in all care settings.

- Using Independent Mental Capacity Advocates (IMCAs) to ensure the voice of the person with a learning disability is heard in decision making. A focused session has already been delivered by the Acute Liaison Nurse team to geriatric clinicians working in University Hospitals of Leicester NHS Trust.

- The use of RESPECT forms as part of the new approach to end of life care.

- The clear recording of Mental Capacity Assessments and Best Interest decision making.

5.9 The fourth theme is diagnostic overshadowing. This means:

- Mandatory learning disability and autism training for all health and social care staff.

- That someone having a learning disability or cerebral palsy is never the recorded rationale for a DNACPR. This has happened in LLR but was quickly addressed by the Acute Liaison Nurse team.

5.10 The fifth and final theme is the role of carers in diagnosis and case management. This means:

- Recognising the benefits of family and carers supporting people with a learning disability in hospital settings.

- That the voices of families and carers are an integral part of the diagnostic process and approach to case management.

- The implementation of the new 'Helping me in hospital' resource to support communication between carers and hospital staff.

"Very clear documentation. Dad was supported with lengthy discussion and support. DNACPR put into place following best interest discussion. Lots of compassion shown within the notes. Palliative care team involved, X was placed on midazolam and morphine infusion. X passed away at 20:35 with all of his family by his side. All religious and cultural support offered following X's death with family."

An extract from an LLR LeDeR Review. This encapsulates the successful application of several of the themes outlined in Section 5 'Indicative learnings and our initial response'.

6. LLR Performance against the LeDeR Key Performance Indicators

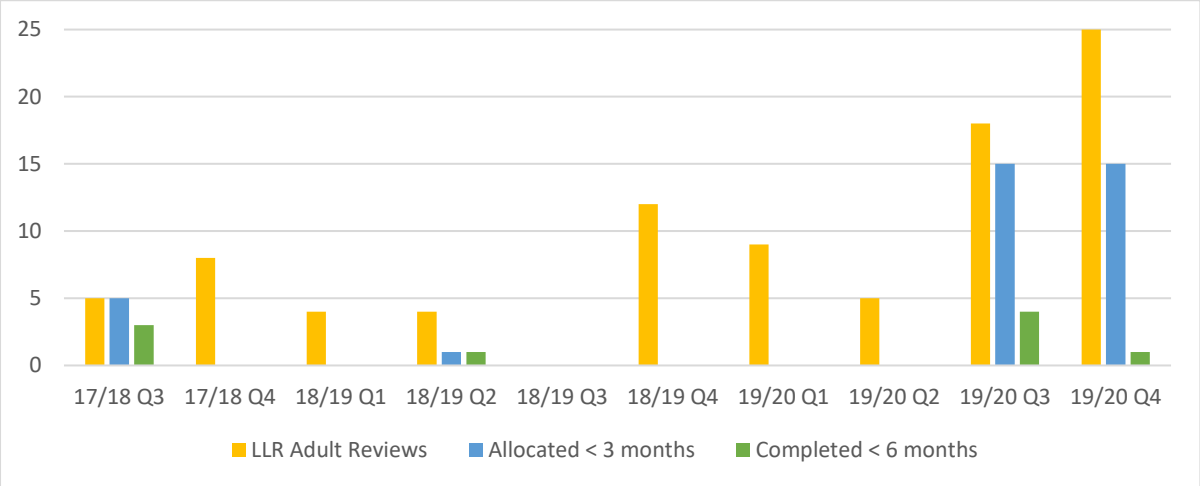
6.1 There are four statements regarding the LeDeR programme that NHS England require each CCG or CCG partnership to report against. LLR performance against each of these statements is outlined below.

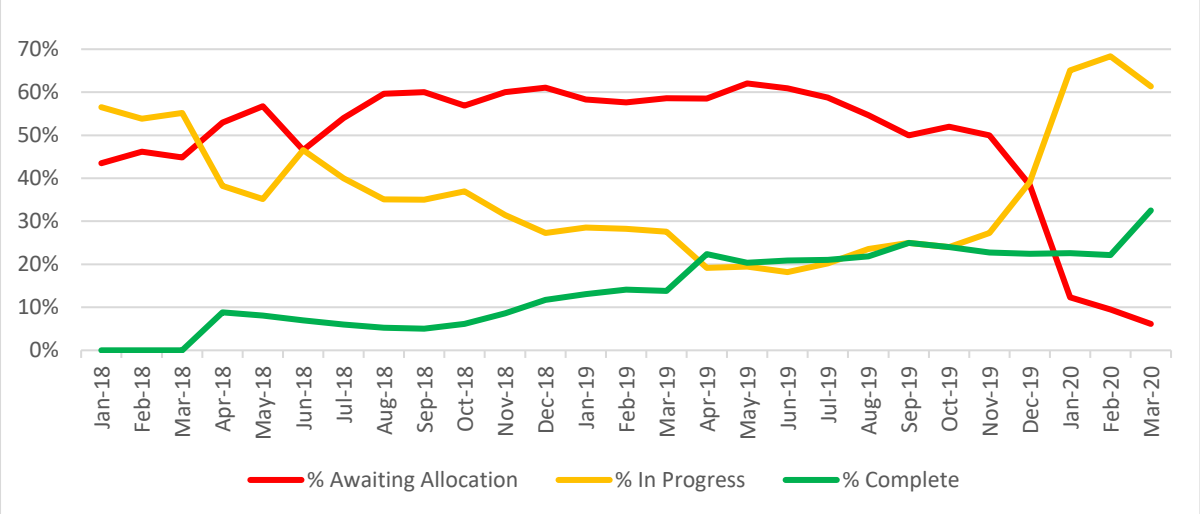
1. **Clinical Commissioning Groups are a member of a LeDeR Steering Group and have a named person with lead responsibility.**

Fay Bayliss, Deputy Chief Nurse, is the Clinical Commissioning Group named person with lead responsibility.

2. **There is a robust CCG plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of death to the local area.**

As indicated in the charts below there has been a significant improvement in performance since Quarter 3 2019/20. This has been the result of greater investment in the programme; investment that LLR has recommitted for the next financial year. It should be noted that performance for each quarter can only be confirmed six months from its final day. It is therefore anticipated that performance will continue to improve throughout the year.





3. Each CCG has systems in place to analyse and address the themes and recommendations from completed LeDeR Reviews

LLR has a Local Area Contact which focuses on Clinical Quality. In addition to the 'Indicative learnings and our response' included in this report LLR will roll out its approach to 'Learning into Action' over the next 12 months. This includes the publication of a 'Learning into Action' report.

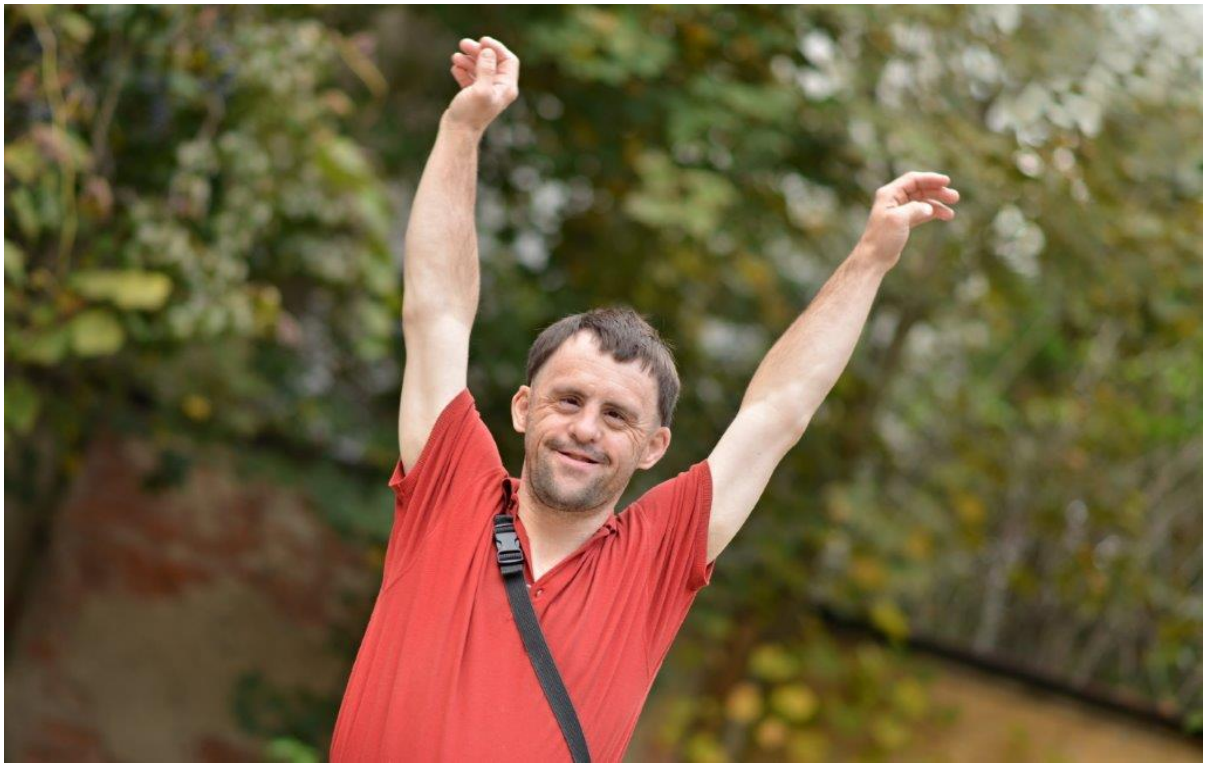
4. An annual report is submitted to the appropriate board/committee for all statutory partners demonstrating action taken and outcomes from LeDeR reviews.

This report represents the first step in meeting this commitment. The second is the publication of the first LLR 'Learning into Action Report' within the next 12 months.

Could D have received better care? Yes, certainly. He would have benefited from additional mental stimulation and social interaction during the early part of the care process. D became a 'ward' of the social care process. We all know that this is fundamentally flawed - not the least of these being financial constraints that impact upon the availability of services and resources at every level.

Did this have an effect on D? Most certainly. D was a prisoner of his physical and mental condition and in order to 'fit' into the care programme he inevitably became institutionalised. That is not meant to be a criticism. It is just a fact."

Feedback from a family member included in a LLR LeDeR Review. These are the some of challenges that LLR needs to address in order to improve the lives of people with a learning disability.



7. Local achievements and areas for improvement

7.1 Outside the LeDeR Key Performance Indicators the following represents some of our local successes that should be recognised.

7.2 The quality of completed LLR LeDeR reviews is high. Each is a coherent narrative of the person in the final episode of their life; extensive in scope and considered in analysis. This not only means that justified learnings and recommendations can be identified but, critically, that it does justice to the person, their family and friends. This is driven by the experience and expertise of local reviews and the continued implementation of local quality standards.

7.3 Local partners have developed processes to aid the LeDeR programme. This includes ensuring that people with learning disabilities who pass away are referred; and that local reviewers have quick and efficient access to the appropriate information required to complete reviews.

7.4 Compared to other LeDeR footprints there has been significantly more engagement from the local authorities. This includes the nomination of LeDeR Reviewers, Steering Group Chairs and, uniquely for the East Midlands, a Local Area Contact.

7.5 The local position against NHS England KPIs has greatly improved in the final six months of the 2019/20 financial year. Without the support of local partners this would not have been possible.

7.6 The Steering Group has recently sought to recruit LeDeR Reviewers from outside the typical pool. This includes approaching Clinical Specialists and a local University Professor who has experience in learning disability services.

7.7 However, there are also several aspects of the delivery of the LeDeR programme in LLR that requires improvement. These are summarised below.

7.8 Whilst the speed at which LeDeR Reviews are being completed has improved, more can still be done. Too often progress is inhibited by the information reviewers need not being readily available. Bringing on board administrative support and recent engagement with the three LLR CCG Clinical Chairs should go some way to addressing this issue.

7.9 Learnings and recommendations have been identified for every completed LeDeR Review. However, the LLR approach to 'Learning into Action' is still in development.

7.10 All stakeholders should be an equal partner in the delivery of LeDeR in LLR. This includes people with learning disabilities and their families and carers. This will be an area of significant focus for the coming twelve months.

10%	Of LLR LeDeR referrals to date are for people with a learning disability who died during childhood. These children often have significant life limiting conditions. That being said their quality of life should be no different to any adult with a learning disability. This is why a close relationship between the Child Death Overview Panel and the LeDeR programme is so important.

8. Priorities for the next 12 months

8.1 In March the LLR LeDeR Leadership Team & Steering Group identified the following priorities for the 2020/21 financial year. These were separated into those that needed to be delivered immediately (April – June) and those which would take longer to achieve.

Immediate (April - June)

8.2 Establishing the LLR approach to LeDeR during the COVID-19 pandemic. This not only includes the completion of the COVID-19 'rapid response' reviews but also how non COVID-19 related LeDeR reviews can continue to be progressed despite some limited access to case records.

8.3 Implementing a local, sustainable approach to Quality Assurance to meet increasing demand.

8.4 Continuing to collate learnings and recommendations from completed Reviews, including from the first learning disability themed CDOP panel.

Longer term (April – March 2021)

8.5 Engaging with partners across the health and social care system about this Annual Report and the initial findings within it. This will drive local conversations about and more importantly the changes needed to improve the quality of services for people with a learning disability.

8.6 The publication of the first LLR LeDeR 'Learning into Action' LeDeR Report. This will be supplemented by a further approach to feeding back to organisations specific actions identified for them by LeDeR Reviewers.

8.7 Strengthening the LLR approach to LeDeR Reviewer peer support. This includes committing to the delivery of four LeDeR Reviewer development sessions over the next 12 months. It is anticipated that this will be led by the LLR LeDeR Clinical Lead.

8.8 Ensuring that part of this peer support is that LeDeR Reviewers fully understand the scope and application of annual health checks, national screening programmes, Stomp & Stamp and any other identified 'gaps' in knowledge. This will ensure that LeDeR Review findings are accurate and that the LLR LeDeR programme contributes to the ongoing personal development of local health and social care staff.

8.9 Working in partnership with all stakeholders. This will be achieved through an LLR LeDeR Engagement Strategy. Family and carer input is already an integral component of each LeDeR Review. Our ambition is to build upon this by making all key learning disability stakeholders an equal partner in LeDeR programme delivery. This includes the approach to 'Learning into Action'.