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LeDeR programme review

Ipsos MORI

Contents

Glossary

CCG: Clinical Commissioning Group

CIPOLD: Confidential Inquiry into premature deaths of people with learning disabilities

ICS: Integrated Care Systems

NHSEI: NHS England and NHS Improvement

LAC: Local Area Contact

LeDeR: Learning Disability Review of Mortality

STP: Sustainability and Transformation Partnerships

1 Executive summary

Background and methodology

- The Learning Disability Mortality Review programme (LeDeR) was established in 2015 by NHS England as a service improvement programme. It has two main aims: (1) to support improvements in the quality of health and social care service delivery for people with learning disabilities, and (2) to help reduce premature mortality and health inequalities for people with a learning disability.

- The LeDeR programme is currently going through a period of transition, as NHSEI looks to set the future direction of the programme. NHSEI commissioned Ipsos MORI to undertake a review of the existing LeDeR programme, engaging with a number of stakeholders to ensure a variety of viewpoints were captured.

- A total of 54 in-depth interviews were carried out with a wide range of stakeholders: commissioners, healthcare providers, LeDeR workforce, social care providers, voluntary sector organisations, LeDeR experts (academics and policy experts), bereaved families, and people with a learning disability and their carers.

Overarching views of the LeDeR programme

- The LeDeR programme plays a central role in gathering critical and robust evidence on the issues faced by people with a learning disability across different care pathways locally and nationally.

- Stakeholders involved in LeDeR delivery highlighted how working on the programme had benefited their personal and career development and contributed to their greater understanding of the local health and social care system.

- However, it was felt that overall LeDeR’s impact has been limited so far, although it was recognised the programme is relatively recent. At a local level, the impact of the programme was seen to vary greatly between CCGs and it was suggested that a statutory process would help LeDeR to be more impactful on driving service change. At a national level, there was consensus that LeDeR’s impact on policy-making was unclear, and probably limited.

The LeDeR review process

Stakeholders identified a number of barriers and facilitators to conducting LeDeR reviews. These included:

- The challenge for LeDeR reviewers to make time to prioritise reviews whilst also managing heavy workloads and the responsibilities of their day to day role. It was suggested that the reviewer role should be made part of job descriptions.
- The diversity of the LeDeR workforce could be both a barrier and a facilitator to the delivery of good quality reviews. While different reviewers bring a range of perspectives and experiences to the reviews, this can also sometimes result in a lack of consistency in the ways reviews were carried out.
- The current training provision for reviewers was broadly perceived to be too limited as it does not include any hands-on training into how to carry out reviews, and wider training aiming to foster greater engagement with families and carers.
- LeDeR reviewers would benefit from more support and training to help build their confidence in carrying out reviews. This includes administrative support which could greatly alleviate reviewers' workloads.
- Other barriers reported by the LeDeR workforce included: the lack of user-friendliness of the web-platform and its lack of functionality (which meant it was challenging for the LeDeR workforce to produce internal reports for their own CCGs), alongside the variable quality of notification of deaths.
- While six months was overall perceived as a reasonable amount of time to expect reviews to be completed, participants wanted to see more flexibility around specific cases – to allow more time for more complex cases, or when it might take longer to successfully engage families.
- Overall, participants wanted to see greater cooperation between different review processes, favouring the alignment of existing review structures rather than having them competing with each other for the information.

Providers and members of the LeDeR workforce highlighted how engagement between the two could vary. For example:

- The LeDeR workforce noted how they could struggle engaging with GP practices and social care providers in particular, especially if they had no or little awareness of the LeDeR programme. Other engagement barriers included the lack of a legal requirement for provider organisations to share a person's records with reviewers, and issues around GDPR and data protection.
- Providers felt that pre-existing relationships with reviewers were key to their successful engagement. They wanted reviewers to take the time to engage and communicate with them throughout and beyond the review process, including being given enough notice by reviewers requiring their input, given feedback on their input in the reviews, and kept informed of the outcomes and action points from reviews.

There was a wide consensus that families and carers ought to be the key focus of reviews and their involvement was instrumental to building a holistic view of a person's life. However:

- Willingness to engage could vary widely.
- Lack of awareness of the programme and lack of clarity about the aims of LeDeR, can be key barriers to families engaging with the programme. Much earlier communication with bereaved families and carers could help to develop some awareness of the purpose of LeDeR before their input is needed.
- Meaningful engagement was viewed as being largely dependent on the skills and confidence displayed by a reviewer. Overall, it was felt that more training on how to engage with bereaved families appropriately was needed.
- There was also a view that reviews would benefit from also speaking to friends of the person who died. This would allow reviewers to gain a more holistic view of a person's life and may uncover findings about their life situation and care.

Sharing learning and action from learning

Overall, stakeholders felt the impact of the programme has been limited so far. The focus of the LeDeR programme to date was described as being heavily on completing reviews, and identifying problems. To date, this has limited translation into wider action to improve services, and action is happening inconsistently across CCGs.

- The annual reports were described as a strength of the LeDeR programme. Those involved in local service delivery reported using them to identify priorities for their local services. There were examples of stakeholders using the recommendations from the annual reports as a starting point for local action planning.
- Participants working at a local level would like to see more regular, informal feedback throughout the review process so that learning can be continuously shared.
- Stakeholders would like a greater focus on what is being done to take learning from the LeDeR programme on board, including sharing best practice locally and guidance on how to implement learning. Suggestions included:
    - More standardised templates and best practice examples provided by the national team to support action from learning.
    - Lowering the threshold for multiagency meetings would allow more of them to take place and drive closer collaboration between different parts of the system.
    - More accountability in local areas but also nationally for acting on the recommendations from LeDeR reviews.

The future delivery of the LeDeR programme

The programme is currently going through a period of transition. To support NHSEI in establishing stakeholder priorities for the future of LeDeR, two specific areas were discussed with stakeholders:

- **Views of reviewing a proportion of deaths rather than every death of a person with a learning disability:** Overall, there was a good level of support for LeDeR reviewing a proportion of all deaths, with some conditions- although some participants felt strongly against this. This was seen as an opportunity to re-focus resources on ensuring learning is taken forward into action. However, there were some concerns that only reviewing some deaths could reduce the amount of valuable learning that can be gained from each death and reduce the overall robustness of the programme. A good compromise for some was to carry out summary reviews of all deaths and then choose cases for an in-depth review.

- **Priorities for the LeDeR workforce in future:** On balance, stakeholders felt that LeDeR reviews should remain the responsibility of local systems, as the most effective way of deriving learning for local service delivery. However, there is an important role for national oversight of this including ensuring consistency, bringing together learning, and assisting areas where there are backlogs.

2 Background and methodology

2.1 Background

The Learning Disability Mortality Review programme (LeDeR) was established in 2015 by NHS England as a service improvement programme following recommendations made by the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)[1].

People with a learning disability often have poorer physical and mental health than other people and may face barriers to accessing health and care services. The LeDeR programme was set up to look at why people with a learning disability are dying at a higher rate, and how local and national services could improve the care offered to people with a learning disability. The LeDeR programme has two main aims:

1. To support improvements in the quality of health and social care service delivery for people with learning disabilities.
2. To help reduce premature mortality and health inequalities for people with learning disabilities.

To achieve this, the LeDeR programme aims to review all deaths of people with a learning disability aged 4 or above[2]. The reviews take a longitudinal approach to capturing a holistic view of the person's life, as well as a history of their experiences using health and care services.

Clinical Commissioning Groups (CCGs) are responsible for ensuring reviews are carried out for all deaths in a local area and ensuring the services they plan and buy change based on learning from reviews. Local LeDeR steering groups, which consist of health and care providers, commissioners, and health professionals in a region, also help to develop plans and make sure lessons learned from reviews are used to improve care. This may include convening multi-agency meetings[3] or engaging with care providers directly to discuss recommendations from reviews.

CCGs also produce annual reports which describe their local action from learning. Currently, the University of Bristol is responsible for coding, collating and reporting on the findings of completed reviews, through regular themed review reports for NHS England. It also produces the LeDeR programme annual report which includes recommendations for the NHS and wider system partners on how to improve services.

Reviewers are responsible for undertaking reviews of the deaths of people with learning disabilities. In general, it is a reviewer in the CCG in which the person lived that will lead the review[4]. As part of conducting a review, reviewers are required to contact family members of people with learning disabilities who have recently died to involve them in the review as appropriate, and work with healthcare and/ or social care providers in order to facilitate the LeDeR process. They are supported by local area

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[1] Heslop P Blair P Fleming P Hoghton M Marriott A Russ L (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Final Report. http://www.bristol.ac.uk/cipold/fullfinalreport.pdf

[2] Although it relies on the completion of Child Death Overview Panel (CDOP) form the for children aged four to 18.

[3] The multiagency review meeting provides an opportunity for those involved in the life and care of the person who has died to gather and discuss the circumstances that led to the person's death.

A multiagency review is always required where the assessment of the care received by the person is graded 5 (i.e. care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death) or 6 (i.e. care fell far short of expected good practice and this contributed to the cause of death.

[4] However, in 2019 NHSEI commissioned the North East Commissioning Support Group (NECS) to undertake some reviews of deaths.

contacts (LACs) who monitor the progress and completion of reviews and provide ongoing advice and support.

2.2 Context for this research

The LeDeR programme is currently going through a period of transition, as it looks to set the future direction of the programme. The majority of its work at the moment is focused on completing reviews. NHS England and NHS Improvement (NHSEI) would like to shift the focus of the programme to increase the pace and quality of reviews, and to have a greater focus on service improvement and addressing the health inequalities faced by people with a learning disability.

As such, NHSEI commissioned Ipsos MORI to undertake a review of the existing LeDeR programme with a number of stakeholders to ensure a variety of viewpoints were captured.

2.3 Key research questions and aims

The research detailed in this report was designed with the following aims and objectives in mind:

- To understand existing perceptions of the LeDeR programme and experiences of taking part in LeDeR reviews (from a range of stakeholder perspectives).
- Identify how key information collected by the LeDeR programme is gathered and shared.
- Explore models for the LeDeR workforce; nationally, regionally or locally commissioned.
- Examine current quality assurance and timelines for completion of reviews.
- Identify key areas where the LeDeR programme could improve and be more impactful.

2.4 Methodology

In order to address the aims and objectives outlined above, a qualitative research approach was adopted, consisting of 54 in-depth telephone interviews. Interviews lasted between 45 minutes and one hour and took place over the phone or via Microsoft Teams. They were undertaken with a wide range of stakeholders, as detailed in Table 2.1.

Table 2.1: Stakeholder categories and number of interviews

Stakeholder type	Number of interviews
Commissioners	10
Healthcare providers	9
LeDeR workforce (reviewers and LACs)	10
Social care providers and voluntary sector	11
LeDeR experts (academics and policy experts)	5

Bereaved families	2
People with a learning disability and/or their carers	7[5]

Ipsos MORI and NHSEI worked in collaboration to identify potential participants. A specialist recruiter with experience recruiting senior figures across the public and private sectors undertook the recruitment.

Easy Read recruitment materials, guides and information packs were created for interviewees with a learning disability to ensure the research was as accessible as possible. This included being flexible in approaches to pace and length of the interview, and to ensure the needs of the participant were met. In line with the legal requirements of the Mental Capacity Act the research did not include anyone who lacks mental capacity to consent to take part.

2.5 Report Structure

The report is structured as follows:

- Chapter 1: Executive Summary
- Chapter 2: Background and methodology
- Chapter 3: Overarching views of the LeDeR programme, which looks at the value participants place on LeDeR and their perceptions of its impact.
- Chapter 4: The LeDeR review process, which explores experiences of conducting the reviews and engaging with the programme, looking more particularly at how the LeDeR review process works within CCGs.
- Chapter 5: Sharing learning and action from learning, which looks at current practices around sharing learning from LeDeR reviews, and actions taken based on this learning.
- Chapter 6: The future of the LeDeR programme, which explores stakeholders’ perspectives on what the programme could look like in the future.
- Chapter 7: Conclusions and implications, which summarises suggestions shared by stakeholders on how to improve LeDeR’s delivery and impact going forward.

Acknowledgements

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[5] ‘Please note that NHSEI plans to undertake further engagement with people with learning disabilities.

3 Overarching views of the LeDeR programme

This chapter presents an overview of participants' views of the programme. In doing so, it summarises the value that participants place on LeDeR, the role it plays in workforce development, and perceptions of its impact and how this may be improved in the future.

3.1 A unique source of evidence

When asked what they value most about the LeDeR programme, nearly all stakeholders commented on the central role it plays in gathering critical evidence on the issues faced by people with a learning disability across different care pathways – both at a local and national level. It was described as a unique, robust and reliable source of evidence. They felt the programme had also raised awareness of issues affecting people with a learning disability amongst those working in the health and social care system. For example:

- Those engaging in the programme at a national level, such as voluntary and advocacy groups, commented on the value of the data and evidence collected in understanding where there may be issues leading to poor quality of care in the health and social care system. They found annual reports especially helpful as a starting point for discussions around how to improve the health and care outcomes of people with a learning disability (see Chapter 5).

- Those working at a local level such as commissioners and health and social care providers felt the evidence provided by LeDeR at a local level informed service change and improvement to some extent, although this varied depending on region. Examples include improving approaches to cancer screening for people with a learning disability, hospital passports, annual health checks, and better links between community and primary care services.

- At an individual level, it was felt pen portraits were a useful method for providing an in-depth and insightful narrative story about the person who had passed away. In doing so, it enabled the patient experience and voice to feed into conversations around service change.

> *"It provides a clear picture on an issue that was poorly understood. It's ensured that there is systematic collection of data and evidence in an area which tends to be overlooked."*
> Voluntary sector

The role of the University of Bristol in providing an independent view across the programme was also valued by stakeholders working at a national level. The annual report provides a comprehensive overview which allows stakeholders to understand issues across England. Stakeholders felt that a level of independence was important for the programme, to mitigate against conflicts of interest within the NHS.

3.2 Benefits to the local LeDeR workforce

Stakeholders involved in LeDeR's delivery agreed that the programme has a positive impact at a local level on the LeDeR workforce. This was especially true as reviewers are drawn from a variety different of health and care backgrounds and may not always provide care directly to people with a learning disability. Benefits to the LeDeR workforce included:

- Taking part in the programme was seen to have benefited their personal and career development, by developing their understanding of what constitutes poor care as well as their investigative and reporting skills.
- Through their work on the programme, reviewers could also develop fruitful relationships with providers and identify practical ways of improving the care provided to people with a learning disability.
- At a wider level, stakeholders involved in LeDeR delivery noted that carrying out reviews allows reviewers to gain a better understanding of the health and social care system. For example, those carrying out reviews said they had gained a greater understanding about how different providers work together (e.g. primary care and community), and where issues can potentially arise where a number of providers are involved in care for a person with a learning disability.
- It also helps raise their awareness of some specific issues faced by people with a learning disability. For instance, one reviewer commented that they were previously unaware health conditions such as constipation were an issue for people with a learning disability and could in rare cases lead to a person passing away.

Overall, the programme was viewed as contributing towards developing a more confident and skilled workforce.

> *"I've found doing the reviews helpful for my own work. They can be a good way to learn about best practice or to remind you how not to handle certain things with a patient who has a learning disability. I like to think the care I deliver for this group is better because of the things I've learnt."* LeDeR workforce

However, commissioners and the LeDeR workforce also suggested that there needs to be more support and training for reviewers, as the experience of carrying out a review can be difficult and stressful. This is discussed in greater detail in the following chapter.

3.3 Impact of the LeDeR programme

Overall, stakeholders felt the impact of the programme has been limited so far. At a local level, the impact of the programme was seen to vary greatly between CCGs. This variation is mainly due to differences in local leadership of the review process and actions to drive change. Where this was not happening, the programme had limited impact.

> *"Good leadership helps and that's made a difference, we need to focus on the long-term changes that we want and have clarity on where and how it can influence. Leadership can't be defensive or brush off these issues, which can happen."* Voluntary sector

It was suggested a statutory process – which health and social are providers need to follow after a review has been completed – would help LeDeR to be more impactful for driving service change (see Chapter 6).

Other challenges to maximising the impact of LeDeR were also identified:

- It could take a long time for reviews to be completed, and therefore for learning to feed through and embed into the local health and care system.
- In some cases, this means the learning can feel out of date and is no longer as relevant to the local system.
- It could also be difficult to precisely determine or attribute the impact of the programme as there were a number of different factors contributing to quality assurance and improvement which can be difficult to disentangle (see Chapter 5).

At a national level, as discussed above, LeDeR's provision of robust data on the deaths of people with a learning disability was highly valued. However, there was a consensus that LeDeR's impact on national policy and decision-making was unclear, and probably limited.

> *"I think nationally it's starting to have impact, raising awareness and the data it makes available. It does really well to highlight national issues. But I don't know how this all feeds into national decision-making. I think that needs government level action in order to really see that, as a health system we are quite fragmented so it's difficult."* Commissioner

It was noted that to date, LeDeR's focus has been on identifying areas of concern, and the same themes have been highlighted each year on year. Stakeholders mentioned that they would like to see a greater focus on actioning learning identified from reviews at all levels of the programme. This is discussed in greater detail in Chapter 5.

4 The LeDeR review process

This chapter explores the delivery of the LeDeR programme, looking at how the LeDeR review process works within CCGs. It examines reviewers' and LACs' experiences of conducting reviews while considering the delivery barriers and facilitators they experience. In doing so, it also explores how families and providers engage with the LeDeR programme – identifying good practice and areas for improvement.

4.1 Delivery barriers and facilitators for LeDeR reviewers

LeDeR reviewers and LACs identified a number of barriers to delivering timely and good quality reviews. In addition to low awareness and challenges in engaging some providers, families and carers (this is discussed in greater detail in Sections 4.2 and 4.3), they described a number of workforce-related and practical barriers, alongside good practice and facilitators to delivering and conducting LeDeR reviews. They also made a range of suggestions about how to improve the delivery of LeDeR going forward.

Lack of time to conduct reviews

One of the main barriers identified by reviewers and LACs was the challenge of making time to prioritise reviews while also managing heavy workloads and the responsibilities of their day-to-day role (the LeDeR reviewer role being usually a secondary job role in addition to the reviewer's main job).

Overall, participants suggested that it was important for reviewers and their employers to create the protected time needed to carry out a review, with some suggesting this should be made part of job descriptions.

> *"The LeDeR programme has an ambition to do a very important piece of work to identify system failure and put it right, but they're asking those people to review those cases on top of already hugely pressured clinical jobs, and I just don't think it works."* LeDeR workforce

Some reviewers also felt that the pressure to 'chase' a delivery target to complete a set number of LeDeR reviews could take away from being able to focus on learnings from reviews and implementing recommendations.

Diversity of the LeDeR workforce

It was felt that the diversity of the LeDeR workforce could be both a barrier and a facilitator to the delivery of good quality reviews. While different reviewers bring a range of perspectives and experiences to the reviews, this could also sometimes result in a lack of consistency in the way in which reviews are carried out.

> *"If you've got a very wide range of reviewers from different professional disciplines and different organisations, I think that's one of our strengths locally, that you then have a lot of different perspectives going on in the reviews (…) The flip-side of that is that you can also have some variability in quality*." LeDeR workforce

Training and support for reviewers

The current training provision for reviewers was broadly perceived to be too limited as it does not include hands-on training around how to carry out reviews, and wider training aiming to foster greater engagement with families and carers. This has meant that some reviewers feel inadequately equipped to tackle reviews.

Reviewers and LACs wanted:

- More practical hands-on training, preferably in person, with some supervision of reviews.
- More training around safeguarding, health inequalities and cultural sensitivities.

Overall, there was an agreement that high quality and thorough training for the LeDeR workforce is critical and that more support needs to be provided to boost reviewers' confidence and allow them to feel competent in:

- Engaging with the health and social care system.
- Having difficult conversations with family members and managing those empathetically.
- Sharing learning with providers and the wider system.

Stakeholders noted that being a LeDeR reviewer can be stressful, isolating, and distressing because of the subject matter. It was suggested that putting a buddy scheme or support system in place in every CCG might help, with more senior and experienced reviewers or LACs providing advice and guidance. They believed this could help increase reviewers' confidence in carrying out reviews and engaging with providers, families and carers.

In addition to peer support among reviewers, it was felt that LACs have a central role to play in supporting reviewers, while also lending a sympathetic ear when needed. There were some examples of this happening locally already.

> *"I've got a really good support network, because my local area contact is really good and supportive. She's been buddying up with me to do the reviews. I always discuss, before I press the button to say it's finalised, what my recommendations are, what my grading is, and the reason I've come to that rationale."* LeDeR workforce

Reviewers reported that they can spend a lot of time carrying out administrative tasks, for example accessing case notes, or locating missing information from a notification of death form. Reviewers and LACs felt that dedicated administrative support could greatly alleviate their workload, and ensure their expertise is put to better use identifying recommendations and engaging with families meaningfully. There were some examples of this already happening successfully in CCGs.

> *"We have administrative support to input and do the uploading of data into the form (…) When the reviewer gets the information, they've got already a baseline of information, and the first thing we ask them to do is that they then make contact with the family, to ask the family what their concerns are, and talk about that individual."* Commissioner

The web-based platform

All reviews are undertaken using the secure web based LeDeR review system. This stores all review documents additional case notes and supporting paperwork, on an online system.

Members of the LeDeR workforce expressed a number of frustrations around the user-friendliness of the platform. This can mean reviewers spend time navigating the platform rather than focussing on the review and recommendations. These included:

- Dialogue boxes being too small.
- Difficulties in uploading and reading documents.
- Lack of spell check.
- Lack of auto-save function.
- A ‘user-unfriendly interface’, especially hard to navigate for neuro-diverse people.
- Inability to cut and paste from an uploaded document.

Beyond these technical issues, it was felt that the content of the questionnaire itself could be improved. A number of suggestions were made, with some reviewers and LACs wanting the questionnaire to include more free text-box space (to allow them to justify answers, discuss findings and raise relevant points) and be more person-centred rather than condition-centred.

> *“You don't start off reading about [name], aged 37, and lived at home with her mum and her little brother. You don't read about the person. You just start off with this list of conditions which I think is just not very positive.”* LeDeR workforce

Finally, the inability to interrogate databases or run queries was also mentioned as a missed opportunity. It was felt that this limited CCGs’ ability to produce good quality local reports, and therefore to formulate targeted recommendations.

> *“You can't interrogate it or run a report from it in the way we would like to (…) It would be really helpful to be able to search the system better to find individuals quicker, easier to search different recommendations (…) sometimes you have to count things yourself off the screen."* LeDeR workforce

Several participants had developed their own systems and spreadsheets to record and populate all the data they receive from death notifications to be able to get a clear picture of what is happening in their CCG.

Above all, reviewers and LACs wanted to be able to:

- Search the databases to find individuals quicker.
- Produce internal reports for their own CCGs.
- Pull out learning and recommendations rapidly.

The quality of notifications of death is variable

Deaths of people with a learning disability are notified to a single point of contact by anyone who is aware of the death (for example, this could be a family member, an advocate, a GP, a residential care worker). The person reporting the death is asked to provide as much key information as possible, including the details of the person with a learning disability who has died, the contact details of a person who knew them well, known health conditions and cause of death if known.

Overall, reviewers and LACs felt that the quality of notification of deaths was highly variable. This can result in losing a lot of time once a notification is made trying to access basic information about the person and how they died. In worst case scenarios, this could lead to duplication of reviews. As such, participants were keen for some fields in the form for the notification of deaths to become mandatory.

> *"I think there's still confusion around notification of deaths, who should do it, who shouldn't do it, and I think that if there was some mandatory field on that notification of death form, that would enable the reviewer to do their job more swiftly."* Provider

4.2 Engagement between the LeDeR workforce and health and social care providers

Health and social care providers are asked to refer every death of a person with a learning disability over the age of four[6]. As part of a review, a reviewer will liaise with the relevant providers who oversaw the person's care and ask them to provide further details about their care, experiences and the person in general. This section discusses views of the process of engaging different groups in this review process.

Views of the LeDeR workforce

Reviewers' and local area contacts' (LACs) experiences of engaging and liaising with health and social care providers varied across CCGs, but also between different providers. Reviewers identified two main groups they could sometimes struggle to engage with:

- GP practices: It was reported that GPs can be unsure whether they are allowed to share patient records, or reluctant to engage with the programme when they know little about it. In some local areas, establishing learning disability champions in each GP practice had been successful to raise awareness and forge successful relationships.

- Social care providers: Reviewers sometimes found it difficult to identify the right person to talk to within an organisation. Having a nominated person within each provider organisation to complete the notification of death form and liaise with reviewers would be helpful.

Other engagement barriers included:

- The lack of a legal requirement for provider organisations to share a person's records with reviewers.

- Issues around GDPR and data protection, which means some providers are unsure about which data they are allowed to share.

- Limited awareness of the programme, which meant that LeDeR reviews are not always prioritised by providers.

> *"I've had social workers say to me they have to get their legal department involved to give me the records (…) They've point-blank refused, they have no idea about the programme."* LeDeR workforce

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[6] The deaths of children and young people aged 4-18 are reviewed through the Child Death Review process with the findings shared with the LeDeR programme

There was a shared view that existing relationships with provider organisations are critical to establish buy-in. Where those did not already exist, it could be difficult to get information about a person's care.

Views of provider organisations

Providers highlighted that gathering and accessing the necessary information requested by reviewers could be time consuming and challenging, and it could involve a range of individuals and organisations. For instance, some people could change providers over their lifetime so that tracking the relevant documentation could be difficult and result in 'holes' in the timeline of the care provided on an individual.

> *"They sometimes have difficulty getting access to the other trusts' or social services' systems to get any information out. It is very elongated. The reviews take a very long time, much longer than people say they should take if you do them thoroughly."* Provider

Similarly to participants from the LeDeR workforce, providers felt that pre-existing relationships were key to their successful engagement. They were also keen for reviewers to take the time to engage and communicate with them throughout and beyond the review process.

While there were examples of this happening successfully, there were some instances where engagement was poor:

- Reviewers were thought to not always appreciate that gathering the necessary information as part a review could take time or might not be possible. Providers also reported that the quality of information provided for the reviews can sometimes be lacking. For example, record keeping of staff among social care providers was sometimes minimal (as it was not always clear to staff going into people's homes what they should record and what they should not record).

  "All the micro accumulative inefficiencies in terms of people having to access multiple information systems, seek access, get approval, find out, have time, etc. all adds up to a process that in order to do it really well becomes quite time consuming." Provider

- It was felt that reviewers did not always giving enough notice to providers about when their input might be needed; and this was especially important in the context of the current backlog. Additional notice would mean providers can anticipate what is needed from them and ensure they allocate enough time to assist reviewers. As such, good communication was perceived to be at the crux of successful engagement.

  “I think something about understanding [reviewers’] expectations and a timeline for how we, as a provider, can be involved in the process and when we'll be expected to feed in can have an impact on people's feelings around how well they've worked with the programme.” Provider

- Providers noted they were not always kept updated on the progress of reviews and their outcomes. It was suggested that the LeDeR process can feel transactional for providers, particularly if there is limited engagement on a review's progress and with the local steering group.

> *"Myself, or other senior colleagues in our services have never been approached by anybody doing a LeDeR review to talk with us about the learning that they've identified to share what they've picked up."* Provider

Some providers described this as 'a missed opportunity' to learn from one another, and ultimately to deliver better care. Overall, they felt that it was critical to ensure they were included as much as possible throughout the reviews, given feedback on their input in the reviews, and kept informed of the outcomes and action points from reviews.

> *"We don't have the conversations at the time about the learning, and potential actions that could be taken forward, and that is a frustration."* Provider

4.3 Engagement with families, carers and people with a learning disability

Involving families and carers in the review process is a key component of the LeDeR programme. Reviewers are encouraged to support families and carers throughout the entire review process, and involve them as much as they feel able or want to.

Overall, it was also felt that families and carers ought to be the key focus of reviews.

> *"The family really should be kept at the heart of everything. They're the only ones that can tell the story, obviously, from their loved one's point of view. So, it's crucial. You cannot go forward without it."* Family

There was consensus among all participants that involving families and carers in a review is instrumental to building a holistic view of a person's life. Stakeholders agreed that families and carers are often best placed to help reviewers to do so by being 'an active partner' in helping them understand what needs to be looked at and explored as part of a review. It was also advanced that meaningful engagement in the programme could sometimes help bring closure to families and carers, or at least could help with them the grieving process.

Nevertheless, families and carers' willingness to engage could vary widely. While some are very keen to share their views and stories, others do not want to engage at all. As such, although participants believed that families and carers need to be put at the centre of every review, they also accepted that there is no 'one size fits all' approach to engaging with them.

Awareness of the programme and clarity of its aims

Lack of awareness of the programme and lack of clarity about the aims of LeDeR can be key barriers to families engaging with it. Stakeholders mentioned that overall, families, carers and people with a learning disability have a very low awareness of the programme. One stakeholder suggested that a national communications campaign specifically targeting them would help to raise the profile of the programme and may support greater engagement.

Stakeholders also stressed that the purpose of the programme is not always entirely clear to families. For example, stakeholders noted that it is important that families and carers do not see LeDeR as a 'route to justice' or an inquest but a service improvement programme. It was suggested that much earlier communication with bereaved families and carers would help them to understand the purpose of LeDeR before their input is needed.

> *“Getting that message across can be really helpful for bereaved families, because one of the things that bereaved families want more than anything else is for something positive to come out of their child's death.”* Voluntary sector

Those communications around the programme could also place a greater focus on how it could improve the lives of people with a learning disability. One participant mentioned involving people with a learning disability in the refinement of the communications strategy.

> *"It's always looked at a bit of a negative thing, I think. It should be more of a positive thing because of what the outcomes could be. I think just having that knowledge of LeDeR and being able to talk openly to families and carers about it would be beneficial.”* Commissioner

Improving engagement

Reviewers are encouraged to contact and involve families and carers in a timely, sensitive and respectful way. Stakeholders stressed they thought good and meaningful engagement was largely dependent on the skills, confidence and empathy displayed by a reviewer.

The first contact by reviewers with families and carers was seen as being critical to achieving this. Reviewers noted that ‘cold calling’ could be extremely distressing to some families and carers. Several reviewers explained how they would send an introductory letter, sometimes with additional information about the programme (for example, a leaflet or a copy of the annual report) informing them that they would be contacted at a later date. As such, families can reflect and decide whether they want to be involved or not, rather than being ‘put on the spot’.

Following this initial contact, the first meeting between a family/carer and the reviewer was also seen to be critical and to require significant preparation. First and foremost, the reviewers need to display empathy and understanding when meeting families and carers. It was also noted that reviewers need confidence in handling this sensitive situation, as well as ensuring the families have meaningful engagement throughout reviews.

> *“What's really important is to ask the family. And some families will be in a position to talk a lot about their family member and that's what they'll want to do more than anything else, and other families will still be in too traumatised a place to be able to do that. So, there's great skill needed in a way by the reviewer.”* Voluntary sector

However, this did not always happen, and some stakeholders mentioned cases of reviewers demonstrating poor practice, driven by a lack of confidence, time pressures, and what was felt to be defensiveness. On this last point, some participants from the voluntary sector and families questioned the impartiality of reviewers.

> *“It seems to me that with the LeDeR programme as it stands, we're asking the organisation where within that organisation or agency someone has died, to investigate that themselves (…) [families] don't feel they're getting properly heard because there's too much defensiveness for anyone to properly hear what they're saying, if that makes sense.”* Voluntary sector

Overwhelmingly, stakeholders agreed that there is a need for more training for reviewers on how reviewers can engage with bereaved families appropriately, for example, around religious and cultural differences and how this might impact how they would like to engage (as discussed in Section 4.1). In addition, participants wanted to see more systematic signposting of families and carers to support organisations, noting how the LeDeR process might be distressing and some people might require counselling or mental health support.

Other suggestions made to improve how reviewers engage with families and carers throughout and beyond the review process included:

- Checking families' and carers' input with them (i.e. asking them whether the information about their loved one is accurate). Stakeholders mentioned examples of bad practice such as errors contained in the review, omissions or unanswered questions, which could be extremely painful for families and carers.

> *"When you're working with anyone who's traumatised, is that when you've taken information from them and you're writing a report, is always to be checking back with them (…) So, the traumatised family feel they have some ownership in the process, and they've not again had something ripped away from them."* Voluntary sector

- Sharing learnings and outcomes from reviews. In addition to better involvement throughout the review process, participants agreed that families and carers needed to be kept informed of the outcomes of the review. In particular, participants with a learning disability felt that GPs were well placed to do so as they would have known the deceased person well. Participants also stressed that families and carers could also be encouraged to help formulating recommendations (if they wished to). While this is a stated aim of the LeDeR review process, this did not happen systematically.

> *"So, if a review's been done and you've given your heart, soul, and guts almost in giving the interview in the hope that things might be different for somebody else in the future, you kind of need somebody to come back to you, and say, 'Thank you very much. You've done all that, and this is what's happened to your report. This is where it's going, this is the difference it might make, or this is where it's feeding to."* Voluntary sector

Finally, many stakeholders agreed that engagement needs to be widened out beyond families and carers, and that reviews would benefit from speaking to friends of the deceased person. This would allow reviewers to gain a more holistic view of a person's life and may uncover findings about their life situation and care.

4.4 Timescales for completion of reviews

On the whole, stakeholders agreed that six months is a reasonable amount of time in which to expect reviews to be completed – if there is sufficient reviewer capacity to meet this timeframe. However, the timescale for completing reviews needs to be a balance between: being flexible around specific cases; accounting for reviewers' competing workloads; the need to provide learning quickly to both families and services; and the need to maintain momentum.

Stakeholders within the LeDeR workforce pointed out that longer timescales than six months could reduce quality of the data (for example, staff move on, a reliance on recall). They also suggested that there need to be some exceptions to the six-month timeframe, and the opportunity to extend a review in extenuating circumstances (for example, if families need more time to engage, or the reviewer has their own needs to be accounted for – an example of autism was given).

However, there would also be benefits to having a ‘hard’ deadline for reviews, as it would help ensure reviews are prioritised.

> *"If you're given a review, maybe it should be time limited rather than open ended where, 'I've got a load of other jobs to do now, a load of training for the next couple of months, I'll put LeDeR down and not do it."* LeDeR workforce

One of the most important considerations for stakeholders when considering timescales was the role of families. Stakeholders noted that it may be inappropriate to engage families too soon after a bereavement, whereas leaving too much time may miss an opportunity to provide the family with much needed answers. The family’s wishes therefore need to be taken into account when thinking about timeframes. As mentioned above, communication with the family is also important – especially if the timelines are long – as they will likely want reassurances and answers rapidly.

> *“As long as it's kept to six months and that there is some regular communication with families throughout that six months, that's fine…it's all about communication and enabling the family to feel as in control of the process as they can.”* Voluntary sector

4.5 Cooperation between the different review processes

Generally, participants wanted to see greater cooperation between different review processes (for example child death review, safeguarding adults review, review of deaths of people in hospitals)- although there were a few instances of good cooperation happening locally. One bereaved family member who had a learning disability, also suggested that generally there is a need for greater co-ordination between care organisations as well as people carrying out reviews. Particularly, in the first few months after a person has passed away as the family might be contacted by multiple organisations involved in their care.

Some stakeholders involved in local service delivery worried about duplication of work; and the benefits of continuing to complete a LeDeR review once a serious incident or a coroner's inquest happened was also called into question. As such, they favoured the alignment of existing review processes, rather than having them competing with each other for the information.

> *"We need to make sure that that flow of information is into one place and it's actually then helping a single learning development programme rather than it actually being isolated.”* Commissioner

5 Sharing learning and action from learning

This chapter specifically focuses on stakeholders' views of the learning identified through LeDeR and actions taken based on this learning. It explores views of sharing learning, examples of sharing and actioning learning happening at the moment, and how learning could be embedded in the programme further.

5.1 Sharing learning from the LeDeR reviews

The annual reports were described as a strength of the LeDeR programme. Those involved in local service delivery reported using them to identify priorities for their local services. There were examples of stakeholders using the recommendations from the annual reports as a starting point for local action planning. At a national level, they have been used to highlight the systemic problems faced by people with a learning disability and helping to hold the system to account.

> *"I think the last annual report, far and above it was the best one. It's a really good quality. It's an excellent foundation for what needs to be taken forward and where we need to go."* Provider

During the COVID-19 pandemic, the LeDeR programme has provided access to data more frequently (in addition to publishing a short report on the first 50 LeDeR COVID-19 reviews), allowing stakeholders to see data about the deaths of people with a learning disability from COVID-19. This has been really valued by some stakeholders. They wanted to see greater access to data beyond reports in a similar way – for example, quarterly access to the data from LeDeR reviews or ongoing access to allow them to produce of ad hoc reports. They said that this would help the LeDeR programme to be seen as transparent and independent, and support stakeholders to use LeDeR data to drive service change. Other stakeholders also suggested that it would be helpful to have quarterly reports or a report every six months at a national level as this could provide up-to-date best practice and encourage a continuous learning process. Similarly, it was also suggested that more regular thematic reports could help to spread learning and support improvements.

> *"(LeDeR) is one of the best sources we have on deaths of people with learning disabilities from COVID, in the world possibly, and they're producing that information weekly."* LeDeR expert

Furthermore, it was noted that the reports are now identifying the same themes each year; it was felt that the focus to date has been heavily on completing reviews rather than driving action from learning. Stakeholders would like a greater focus on what is being done to take this learning on board, including sharing best practice locally, and guidance on how to implement learning.

> *"We need something that says, these are the common themes for LeDeR, why people are dying. This is what's happening locally to change it."* LeDeR expert

At a local level, stakeholders mentioned a number of different ways in which learning from LeDeR reviews is being shared. These include informal routes – for example, those working for a health provider sharing the learning with colleagues in other providers in their locality. Stakeholders also discussed CCGs and regional teams collating findings from LeDeR reviews in their area to help inform strategy planning and to set priorities for the system. Annual reports were also being used locally to identify areas of good practice and where improvement might be needed at a local level.

However, providers and commissioners agreed that it can take time to receive learning from individual deaths. They would like to see more regular, informal feedback throughout the review process so that learning can be continuously shared – for example through regular conversations with the reviewer as and when learning is identified.

> *"A frustration for me is the duration of time it takes the reviews to be done. Then the route to get the feedback back seems very convoluted. It seems to be that there isn't a process that talks about sharing the learning. No one talks to us about the reviews, where it might be relevant to our services."* Provider

5.2 Embedding action from learning

Overall, stakeholders felt the impact of the programme has been limited so far. The focus of the LeDeR programme to date was described as being heavily on completing reviews, and identifying problems in services delivered to people with a learning disability. Stakeholders thought this has not translated into wider action nationally to improve services and evidence the impact of these changes. This was not seen as the primary responsibility of the LeDeR programme but a wider comment on the commitment from national government and the NHS nationally to transform services for this group.

> *"I don't think there's been much of a national response to the recommendations that LeDeR put out. But I'm not sure I would lay that at the door of the LeDeR programme."* Policy expert

Nevertheless, stakeholders were able to talk through examples of what learning has been shared and how this has been used locally. For example:

- Encouraging clinicians to promote annual health checks to people with a learning disability and their family and carers, following recommendations that more regular check-ups would help prevent premature deaths.
- Using recommendations from reviews to inform awareness training for GPs, with the aim of identifying health issues much sooner.
- Using learning from reviews completed across the region to inform the design of a regional strategy for the care of people with a learning disability.
- Sharing learning from a review with other colleagues working in provider organisations in their locality to help spread learning and best practice.

Yet, stakeholders agreed that there were inconsistencies in the extent to which local areas were sharing learning and acting on recommendations from LeDeR reports. While there were some good examples of local areas acting proactively, other areas were not as active on driving forward action from learning. Stakeholders were keen for the programme to place a greater focus on action from learning in future. Overall, stakeholders including providers, commissioners and the LeDeR workforce felt the programme needs a greater focus on engaging local leadership and those responsible for local service delivery in order to help standardise action from learning.

There were some suggestions for how action from learning can be improved and made more consistent across CCGs:

- **Tools to support action from learning**. Once learning had been identified, it is not always clear what next steps should be taken, and how this should be shared with the different providers in the system. Stakeholders felt that it would be helpful to have more standardised templates and best practice examples provided by the national team to support action from learning. This could include guidance on how reviews should be used to inform local change and examples from exemplar sites about how they have implemented change. This would support local systems to focus more on what happens after a review.

  "What would be more useful, would be more national templates or examples of reports, that say this is what good looks like. And a little bit more national guidance about how reviews get used to inform local change." Commissioner

- **Lowering the threshold for multiagency working**. Multiagency review meetings provide an opportunity for those involved in the life and care of the person who has died to gather and discuss the circumstances that led to the person's death. A multiagency review is always required where the assessment of the care received by the person is graded 5 (i.e. care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death) or 6 (i.e. care fell far short of expected good practice and this contributed to the cause of death). Providers and commissioners reported that lowering the threshold for multi-agency meetings would allow more of them to take place and drive closer collaboration between different parts of the system. This in turn would help to engage all providers involved in service improvement for people with a learning disability.

  "I don't think we've been invited to any multiagency meetings...When you don't have those meetings, you don't have any opportunity to talk together across the system about cross-area learning. I understand everybody's really busy. but I think we're missing out on an opportunity if we're really going to want to make a difference." Provider

- **Greater accountability for making changes in response to recommendations.** Stakeholders would like to see more accountability in local areas but also nationally for acting on the recommendations from LeDeR reviews. There was also a suggestion that CCGs should be accountable to a national oversight group, which would encourage them to implement changes to services consistently. One participant also referenced an ISO standard whereby action to respond to improvements identified are evidenced to the auditor. Overall it was felt that the local governance of the LeDeR programme needs to be structured in a way to ensure recommendations coming from reviews are taken forward. For example; ensuring there are senior accountable members of the steering group, and the steering group has the authority to hold CCGs to account. A few stakeholders noted local steering groups did not always include the right types of people. Stakeholders felt that local steering groups needed to have greater power to implement changes following reviews within their local area and should include a more diverse group of organisations such as social care providers, local charities, families and carers, and people with a learning disability. It was suggested steering groups could also include a CCG board member responsible for LeDeR and tasked with actioning recommendations.

  "Sometimes it feels like we're repeating life on a loop, instead of actually setting ourselves some really clear recommendations (…) For me it's just always tightening the recommendations and then holding people to account to whether they've delivered, or not." Policy expert

- **Creating more space for co-production** with bereaved families, people with a learning disability and their families and carers. Stakeholders across all groups suggested co-production would be particularly useful after learning has been identified, as these groups can provide insight into actions as they are developed. It was suggested that there could be a mandatory requirement that all local steering groups include people with a learning disability, bereaved families and other families or carers, to directly engage them in the formulation of recommendations from reviews.

  "Health care professionals don't understand people with a learning disability well enough. Allowing co-production and showing what the recommendations would mean to someone with a learning disability would help aid understanding." Voluntary sector

- **Greater integration of LeDeR with broader quality assurance and quality improvement processes** at a local level, which could help ensure learnings are aligned and consistent. There are some examples of this happening – for instance one reviewer explained how their local LeDeR function seats in the CCG's quality and safety directorate – this ensured different parts of the directorate were fully sighted on LeDeR's findings. However, this did not happen consistently across CCGs.

- **Measuring the impact of actions:** Finally, stakeholders involved in local service delivery felt that the programme would benefit from a joined-up approach towards measuring and evaluating impact. Stakeholders recognised that it can be hard to disentangle the different factors influencing health and care services, and attribute changes directly to the LeDeR programme. A few stakeholders said that as a minimum there should be local and national 'action tracker' which keeps a record of recommendations and what has happened in response.

  "There should be a log locally to record recommendations and attached to that log should be what actions were taken in response to that (…) Local areas could evidence what they've done in response to recommendations from mortality reviews" LeDeR workforce

6 The future delivery of the LeDeR programme

This chapter explores stakeholder perspectives on the future of the LeDeR programme. The programme is currently going through a period of transition; to support NHSEI in establishing stakeholder priorities for the future of LeDeR, two specific areas were discussed with stakeholders:

- Views of reviewing a proportion of deaths rather than every death of a person with a learning disability.
- Priorities for the LeDeR workforce in future.

These are discussed below.

6.1 Reviewing a proportion of all deaths

Stakeholders were asked for their views on whether the LeDeR programme should continue to review every death in the way it currently does, or instead begin reviewing a proportion of deaths. The benefits of both were discussed, and stakeholders could see the pros and cons of each option. Individuals were also conflicted on this question, with some finding it difficult to settle on an ideal approach.

Overall, there was a good level of support for LeDeR reviewing a proportion of all deaths, with some conditions. This was seen as an effective and pragmatic use of limited resources. Stakeholders within the LeDeR workforce noted that there were often specific deaths where learning can be limited; for example, where someone has died at the age of 85 and their death was to be expected. These stakeholders also noted that a lot of the same learning is being identified within the reviews, so reviewing a proportion would be reasonable.

> *“25% of all deaths, I think you’d still be getting the same picture as if you reviewed 100%, but it makes it more manageable (…) it’s rare, now, that I see a review where a completely new learning point emerges. Most reviews now are just reinforcing what we already know.”* LeDeR workforce

The benefits of reviewing a proportion of deaths rather than all of them includes the potential for higher quality reviews, and more time and resource available for implementing recommendations.

> *“It could become more targeted and rather than trying to look at every death, it looks at specially selected ones rather than trying to cover everything, and moving to a phase where it’s really making a difference.”* Family

However, some stakeholders felt strongly that LeDeR should continue to review all deaths. There were a variety of different stakeholders who felt this way, including stakeholders from health and social care providers, CCGs, and those in voluntary/advocacy groups. These stakeholders were concerned that only reviewing some deaths could be seen as prioritising certain deaths over others. Others felt that it may be possible to use this selectivity to avoid reviewing certain deaths. Reducing the number of deaths being reviewed could also reduce the amount of valuable learning that can be gained from each death, and reduce the overall robustness of the programme.

> *"I think a lot of organisations and families would be devastated at, 'you need to meet a criteria for your death to be reviewed'.(…)I don't think it would have half as much impact as it has now(…)I'm passionate every death gets reviewed."* Voluntary sector

Stakeholders who supported reviewing a proportion of deaths discussed carrying out summary reviews of all deaths and then choosing cases for an in-depth review. This might involve screening reviews, or triaging them. Suggestions for what information should be included in this 'triage' included looking at whether any concerns had been raised about the person's care or their death; contacting the family to see if they have concerns; and initial engagement with coroners.

Stakeholders advised that this process needs to be very carefully scrutinised and managed. Maintaining independence is important, as well as ensuring the LeDeR workforce has the expertise and information available to identify which deaths need looking into in more depth. However, it was also noted by stakeholders in the LeDeR workforce that it can be very difficult to know what is going to be a complex review, or where there have been errors, until the review process has been nearly completed.

> *"You could do a more 'skeleton' review, and then look and see if you've got any issues to then review it more(…)I think that's difficult to do because sometimes it's the very last piece of information I find out that makes me realise that there's an issue that hasn't been picked up."* LeDeR workforce

In terms of what criteria could be used for selecting in-depth reviews, stakeholders had the following suggestions:

- In-depth reviews of all unexpected deaths, or premature deaths.
- Review all the complex deaths, or where there are some safeguarding concerns, and a proportion of the others.
- Selecting a representative sample of deaths to review.
- Focusing on locations/timeframes with particularly high death rates.
- Taking into account the cause of death and where this may not be clear-cut.
- Focussing on specific themes/ areas of concern – for example focussing on a group that is particularly high risk.

> *"Somebody that's in a wheelchair with a severe scoliosis, and they get PEG fed, and they have chest infection after chest infection, and they're youngish…those are the ones that you would learn from because they've bounced in and out of hospital: why didn't we get it right first time? (versus) the ones that have got a clear-cut diagnosis, like a brain tumour."* LeDeR workforce

Stakeholders would also be reassured if families and carers were given the chance to opt into a review if they wish to. One stakeholder also recommended that this staged approach and criteria needs to be properly co-produced with people with a learning disability, their families, and local areas.

> *"People (should) get asked if they want to be part of the review, and people are given a chance to opt in as well. Because if you felt that you'd not had the opportunity to take part in a review and you wanted to, that would be pretty hard."* Voluntary sector

6.2 The future LeDeR workforce

On balance, stakeholders felt that LeDeR reviews should remain the responsibility of local systems, as the most effective way of deriving learning for local service delivery. A number of advantages to preserving local oversight of LeDeR reviews were reported, including:

- **The importance of local relationships with health and social care organisations for carrying out the reviews.** This was identified as a key enabler to carrying out reviews effectively, facilitating easier access to case notes and conversations with local providers. For example, a provider reported that when a reviewer comes in from another area, there can be a reluctance to engage with the review process.

- **Understanding of the local population.** There may be specific characteristics in the local population – for example ethnic or spiritual considerations – that people from outside of the area may not be familiar with, that can hinder learning.

- **The value of reviewers gaining transferable skills through the review process, and the benefit of retaining this learning within the local area.** As mentioned in Chapter 3, stakeholders involved locally in reviews (LeDeR workforce, commissioners) noted that reviews offer a valuable development opportunity for local health and social care staff, allowing them to gain a wider understanding of the health and social care system. They did not want to lose this.

  > *"I have genuinely found that the learning you get from having front-line practitioners contributing is really valuable, and I would hate to lose that…somebody who's actually at the coalface, who understands what's happening today, in real time, in the real world."* Commissioner

There were concerns about making the LeDeR team more central. It was felt that having a central, or national team, would shift the programme's focus towards assurance and oversight rather than about identifying learning for local service delivery. Stakeholders had concerns that this would reduce the richness of learning as reviewers may lack local relationships and knowledge. It was also felt that this could reduce the sense of ownership over reviews and reduce buy-in to review findings.

> *"I think as soon as you start to bring that up to a centralised oversight, you lose all of that rich information about people (…) We have got a regional approach to addressing the backlog of reviews. Those reviewers don't have the relationships with GPs, care homes, local authority, social care commissioners and social workers."* Commissioner

Nevertheless, some advantages to the review process being managed centrally were identified, suggesting there is an important role for a central team to play. The benefits of having central oversight include:

- Improving the consistency of the delivery of LeDeR reviews.

- Increasing efficiency and productivity of the review process, by ensuring there are economies of scale.
- Assisting the existing local teams when needed, for example when backlogs need to be reduced.
- Acting as a point of escalation, and independent oversight.
- Bringing learning together from across the programme, and helping local areas identify areas for action.

> *"There should be a mix of both (local and national oversight). I think developing skills locally is really important, but I think that should be guided by a very strong national team, who are ensuring the quality and consistency of reviews."* LeDeR workforce

There was some disagreement over what level this central team would need to be based at; for example, nationally, regionally, or at a system (e.g. ICS) level. Stakeholders recognised the benefits of each.

Reassurance that reviews are independent and avoiding conflict of interest was an important factor for stakeholders, and they would like to see this built into the structure of the workforce. There were some concerns that local areas conducting their own reviews has a conflict of interest, especially when someone is conducting a review within their own hospital trust. However, it was also noted that because reviews need to be carried out by people with specialist expertise, it can sometimes be difficult to identify someone who has the necessary expertise outside of the organisation. Suggestions for resolving this included having a safeguarding mechanism such as an independent body that can be called upon in cases where this was a concern. It was also suggested that reviewers could be shared between trusts to ensure reviews are not conducted by a trust employee.

> *"I think reviewers need to be not employees of the trust that they're reviewing…you could see swap deals between organisations, or reviewers employed in one trust doing reviews for somewhere different and vice versa."* LeDeR expert

Participants also noted that it is critical that reviewers have the right expertise – for example, clinical expertise relevant to the person and their cause of death.

> *"The key thing is having expertise in learning disability services, and where possible if somebody's died of a particular condition, some awareness and knowledge of that as well. "* Provider

6.3 Strengthening LeDeR's mandate

Because LeDeR is not mandated, some stakeholders strongly believed that the work involved in carrying out LeDeR reviews can sometimes be deprioritised given other competing commitments. LeDeR workforce and providers noted that they sometimes had to do this themselves as they do not have protected time to commit to reviews. It was felt that having a statutory process in place could ensure that all deaths are investigated, and also secure greater engagement of health and social care providers. This was seen as key to helping LeDeR be more impactful for driving service change. A few stakeholders also mentioned that the LeDeR programme should be incorporated into the work of the Care Quality Commission in order to provide that statutory power.

> *“Coroners are mandated and you’ve got to attend and you’ve got to send reports. You have got to do that (…) A child death review, you need to do it. Investigations like safeguarding are mandated (…) So, the other [reviews] are at a much higher level than LeDeR, and I think people see LeDeR a bit different to the others. It’s not as robust.”* Policy expert

7 Conclusions and implications

The LeDeR programme is greatly valued by stakeholders for the wealth of evidence and insights it yields. Overall, stakeholders felt its impact, both at a national and local level, has been limited so far, noting that it is still ‘early days’. Yet, there was also a sense that LeDeR was gradually gaining impetus. There was a hope, shared by all, that the programme’s impact would grow overtime.

As highlighted throughout the report, stakeholders shared a range of suggestions to improve LeDeR’s delivery and impact going forward.

7.1 Improving the delivery of the LeDeR programme

Stakeholders involved in the delivery of the LeDeR were in agreement that reviewers would be in a position to conduct a greater number of good quality reviews if the following actions were taken:

- **Improving the skills of the LeDeR workforce** through the provision of additional training. This should be around safeguarding, health inequalities and cultural sensitivities, as well as practical, hands-on training.
- **Freeing up time for reviewers to carry out their role** by providing administrative support when needed, and by having the LeDeR reviewer role as part of a job description. This would ensure reviewers have protected time to carry out reviews.
- **Providing additional support** and, in doing so, increasing reviewers’ confidence in dealing with providers and families. Putting in place a buddy or peer support network system were seen as possible ways of doing this.
- **Allowing some flexibility within the six-month timescale** to allow more time for more complex cases, or when it might take longer to successfully engage families.
- **Tackling inefficiencies and practical barriers to delivery** by improving the current layout of the web-based platform, its functionalities, and the notification of death process (with some fields in the form for notifying of deaths being made mandatory).
- **Encouraging greater cooperation between different review processes** to avoid duplication of efforts and families/carers being asked the same questions by different review panels.

7.2 Improving engagement with providers

Reviews could be conducted more quickly, and learning shared more effectively, if the following improvements are made:

- **Increasing awareness of the programme among GPs and other providers** through targeted communication, as providers can be reluctant to engage and know little about the programme when reviewers engage them.
- **Early and regular communication between reviewers and providers** on a case by case basis. This is critical for providers, especially with the current backlog, so they can anticipate what is needed from them, and ensure enough time is allocated to assist reviewers.

- **Ongoing sharing of learnings with providers**, through proactive and constructive conversations, so they can get feedback on their input and to allow improvements to be made more rapidly.
- **More multiagency working** and meetings to encourage service improvement.

7.3 Improving engagement with families and carers

There was an overwhelming view that families and carers should be the key focus of reviews. Stakeholders made a number of suggestions to ensure families and carers are engaged meaningfully in the reviews:

- Ensuring families and carers to have a **clear understanding of the aims of LeDeR**, and how and why their contribution matters. Much earlier communications with families following a bereavement could help.
- **Reviewers need to display empathy and understanding when meeting families and carers.** This means reviewers need to develop the right set of skills to deal with them respectfully and mindfully from the very first point of contact (by avoiding ‘cold calling’) but also throughout the reviews (by showing them how their input is valued). It is also important to give them the opportunity to feedback on what reviewers write about their loved ones.
- Linked to the above, reviewers also need to **signpost families and carers to support organisations.**
- **Engagement beyond the review process could be beneficial,** by keeping families and carers informed of the outcomes and action points from reviews, and by involving them in the formulation of recommendations if they wish to.
- **Engagement should be widened beyond families and carers** to include friends, and other people with a learning disability as part of a review.

7.4 Improving sharing and action from learning

Stakeholders’ priorities for the LeDeR programme in the future focussed on a much greater focus on sharing learning and action from learning. It was noted that to date, acting on recommendations from LeDeR reports had been inconsistent; some areas have been very proactive and others less so.

> *“Far more follow-up work needs to be done to monitor the actual learning that's gone on; on a local and a national basis. There's no point keeping on reviewing deaths forever more, it's what is learnt from those reviews.”* Family

Stakeholder recommendations focussed on:

- Identifying **where learning has led to service improvement** and sharing this learning. This may involve agreeing how the impact of learning can be measured.
- **Including more co-production elements throughout and beyond the review process** by involving people with a learning disability, families, and carers in the review process and how changes will be made to tackle issues.

- **Strengthening local and national governance around LeDeR** to ensure that CCGs are held to account for actioning recommendations made within the reviews.
- **Improving the outputs from the LeDeR programme, including:**
    - **Creating tools for service improvement locally**, for example national templates or examples of best practice, to support local systems to come together and drive change.
    - **Improving the web platform** to allow CCGs to run queries and create reports based on local evidence. This would help local areas identify learnings and to communicate these. It would also allow CCGs to see how they perform at a national level and compare to others.
    - **Greater access to data beyond reports**, as has happened during the COVID-19 pandemic.
    - **A greater focus in the annual reports on good practice, and shared learning** to demonstrate how the programme is helping improve services in CCGs.
    - **Regular thematic reports** which could help local systems tackle specific issues**.**

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