East Midlands Academic Health Science Network
Igniting Innovation

LeDeR managing deterioration programme

Midlands region

Final report

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Directors of adass adult social services East Midlands
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west midlands ACADEMIC HEALTH SCIENCE NETWORK
East Midlands Academic Health Science Network Igniting Innovation
NHS

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1. Executive summary

NHS England and NHS Improvement (NHSEI) Midlands region received national LeDeR (Learning Disability Mortality Review) programme funding to commission a programme to explore and test approaches to the management of deterioration among people with a learning disability receiving care from supported living providers.

Individuals from multiple organisations worked collectively with the common goal of improving health outcomes for people with a learning disability. In the spirit of co-production and keeping the individual at the centre of all actions and decision-making, this programme has taken a detailed look into the planning, and delivery of care in relation to prevention and management of deterioration.

During the diagnostic phase, the programme obtained evidence from related literature, observations of stakeholder experience and quantitative data collection through semi-structured interviews to map existing processes and practice. This learning was applied to understand the reasonable adaptations that could make these practices more effective for individuals with a learning disability, residing in supported living accommodation.

During the pilot phase of the programme, quality improvement methodology was applied to test potential approaches, tools and interventions in a real-world environment.

This report presents the learning from the programme, believed to have positive potential to make a significant difference in improving health outcomes. Recommendations for consideration for further larger-scale programmes to enhance learning have also been included.

The programme is intended to give a voice to individuals with a learning disability, ensuring they and the people who provide their care, are central to designing and mapping out solutions related to early health deterioration.

In summary, the programme's activities included:

- Agreeing a partnership between NHS England and NHS Improvement, East Midlands and West Midlands Academic Health Science Networks (AHSN), and East Midlands and West Midlands Association of Directors of Adult Social Services (ADASS) to deliver this project.
- Securing the commitment of the Directors of Adult Social Services of four local authorities, who gave unanimous support for the programme.
- Developing a stakeholder map, including primary care network leads and self-advocacy organisations.
- Agreeing the methodology that would best lend itself to quality improvement work, underpinned by the national PIER framework (see below).
- Selecting three deterioration management tools to be tested, respecting the existing preferences of local clinical commissioning groups.
- Developing an additional bespoke, accessible tool specifically for the pilot phase.
- Identifying supported living providers in the four programme sites that were willing to participate in the pilot phase.
- Developing resources in Easy Read and other formats.

- Developing a safety cross for use by support providers.
- Providing training on the selected tools and quality improvement methodology.
- Explore and understand challenges to introducing change in social and health care processes and systems.
- Conducting surveys and semi-structured interviews with a wide range of stakeholders.
- Gathering feedback throughout the pilot phase of the interventions used.
- Reflecting on the learning from the real-world testing phase and explore potential recommendations from the programme.

The programme has generated real collaboration, enthusiasm and commitment from its partners, highlighting the following key learning points:

- Signs of deterioration are more easily recognised by support workers who have a consistent and longer-term relationship with an individual. Detection of deterioration can be more challenging for agency and short-term staff.
- GP continuity and long-established healthcare relationships lead to higher quality interactions and responses.
- Elements of the PIER framework are already used by support staff in an non-structured means. Tools tested gave structure to the recording and escalation of concerns which was positively received.
- Poor communication between care teams and clinical staff is a barrier to optimal clinical care provision, especially with limited consultation time. GPs welcome the use of tools to help structure communication between support staff and clinical teams.
- Training on the use of tools and quality improvement techniques is key to change management.
- Safety crosses were found to be a useful approach to track people's wellbeing but are hard to include in digital patient records.
- Working collaboratively across health and social care has led to proactive care for individuals.

The overarching recommendation is to build on the initial learnings by extending this programme to include a larger cohort of individuals across a wider geography. Care needs to be given to understanding the process, collaboration, and approaches to measuring a variety of inter-relational outcomes. Co-production is vital to working with organisations who have very different practices, cultures and systems. Further recommendations include:

- Co-production is key and needs to form the basis of the whole approach going forward.
- Clear escalation pathways need to be developed by the whole integrated system.
- Development of opportunities to enhance proactive health checks, clinical reviews, and connecting people with a learning disability to other clinical services.
- Multi-disciplinary drop-in style cafes and catch-ups could be helpful.
- Built-in measurement plans from the outset of the programme to evaluate clinical outcomes, system efficiencies, resource allocation and cost savings.
- Embedded soft signs tools and escalation routes across all providers with appropriate training.
- Continue to lever quality improvement approaches to make simple improvements in a complex system.

Examples of the pilot in action

A person with epilepsy received a medication review from a specialist, who changed their medication. However, due to a failure in communication between the surgery and pharmacist, the medication change was delayed, and the person was admitted to hospital. There was a delayed discharge of two weeks, whilst the correct medication was arranged. Better communication could have prevented this from happening.

One individual consumed a high level of alcohol around pay day, and multiple interventions failed to resolve this. By using the safety cross, the person was able to see the consequences of their actions through the number of 'red' days. Through discussion with them, they were able to reduce the number of red days and required fewer interventions from health and social care services.

One person fell after having a Covid jab and their arm began to swell. Despite escalating this, it was incorrectly linked to the Covid jab, and their fractured shoulder was missed. Subsequent impact led to severe pain for many weeks. Longer term, this affected the person's independence, leading to increased care costs. With a more visible pathway, that took account of exceptional circumstances, could have supported earlier intervention.

During an evaluation of an individual's 'soft signs' of deterioration, a staff member used an oximeter to measure the person's oxygen saturation. This helped pick up low O2 levels, which led to a speedier admission to hospital.

2. Introduction

The National LeDeR report evidenced that people with a learning disability die prematurely with conditions that could have been prevented or were amenable to treatment. It showed that commonly occurring causes of death included pneumonia, aspiration pneumonia, sepsis, ischaemic heart disease and epilepsy. 29% of individuals with a learning disability whose death was reviewed lived in a supported living setting (LeDeR Report 2019). The report further explains how signs of health deterioration for people with a learning disability are not always promptly detected by carers, and that concerns expressed by carers to health professionals are not always taken seriously or responded to in the most appropriate way.

The National LeDeR programme, through NHS England and NHS Improvement Midlands Region Learning Disabilities & Autism Team, commissioned a regional programme to explore and test tools available for the detection and better management of deterioration among people with a learning disability, who reside in supported living settings or receive care at home from supported living providers.

The programme was led by East Midlands and West Midlands Academic Health Science Networks (AHSNs) working in partnership with the East Midlands and West Midlands Associations of Directors of Adult Social Services (ADASS).

Using quality improvement methodology, action learning and appreciative inquiry, the programme tested the implementation of deterioration tools within supported living care services to better understand:

- Factors which impact implementation.
- Capacity and capability within supported living services to implement the use of tools and to apply quality improvement approaches.
- Adaptations required to make tools sensitive to the needs of the client group.
- Opportunities for the deployment of digital tools.

This programme aimed to identify which approaches and interventions work best to support better identification and timely escalation of health deterioration. It builds on the firm foundation of programmes undertaken by other organisations, including University of Bristol and West of England AHSN.

The testing was framed around the PIER (Prevention, Identification, Escalation and Response) framework. This framework was developed by NHSEI's national patient safety team and is used within its national Managing Deterioration Safety Improvement Programme.

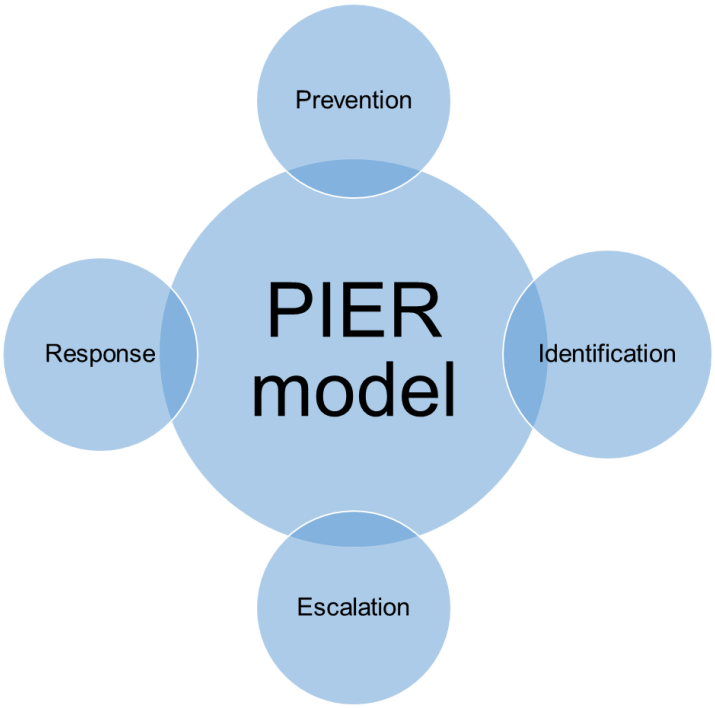

Figure 1: The PIER framework

Prevention: Approaches to prevent deterioration may include care planning / education / reviewing pathways. Consider how safety culture in supported living settings supports prevention of deterioration.

Identification: Test assessment tools and scope potential for remote monitoring. Consider user-led/carer-led and passive models and their adaptability to the bespoke needs of the end user.

Escalation: Assess how the escalation is communicated and received. Test the impact of structured escalation tools in this context. Consider the pathway design that supports implementation.

Response: How is the escalation being responded to. Consider the needs across the pathway to enable an appropriate clinical response.

The following shortlisted tools were subjected to the real-world testing phase to understand the methodology for successful implementation, suitability and requirements for adaptations.

Prevention	Annual Health Checks and Health Action Plans for people with a learning disability, Covid vaccination information
Identification and Escalation	RESTORE2*mini* for LD with SBARD Stop and Watch for LD with SBARD Is My Resident Unwell? for LD with SBARD Keeping Well Tool with SBARD
Response	Measure the response to the use of the above, as well as explore avenues supported by systems involved in the pilot

Deterioration tools combine soft signs recognition prompts alongside an SBARD (**S**ituation, **B**ackground, **A**ssessment, **R**ecommendation and **D**ecision) communication escalation pathway. 'Soft signs' refers to observed changes in a person which may suggest early deterioration such as changes in mobility or appetite.

The pilot involved:

Feedback from the collaboration event

'The pilot generated real collaboration between partners working together to make a difference.'

'Real enthusiasm, passion and commitment to reducing health inequalities evident at every stage of the pilot.'

3. Methodology

The programme commenced with a diagnostic phase to review the available literature, scope existing practices (work as done) and to gather baseline information. This included collecting stories of experience, gathered using semi-structured interviews with people engaged in the care pathway. Interviews were conducted with health and social care workers with professional involvement and with people with lived experience of living with a learning disability or providing care to someone with a learning disability.

This intelligence enabled exploration of potential approaches to better detecting and managing clinical deterioration within this context. A shortlist of promising interventions was selected to be tested further during the programme pilot phase implement. This is further referenced within the interim report.

The programme worked alongside individuals with a learning disability who receive a varying range of care from a few hours per week to 24/7 support. Four pilot sites were identified to include a mixture of urban and rural areas, and to ensure a demographic mix in terms of culture and ethnicity was reflected. These were:

- Nottinghamshire
- Lincolnshire
- Walsall
- Herefordshire

The project team identified potential tools for testing within supported living services. A bespoke tool ‘Keeping Well’ was also developed as part of the programme. The list of potential tools was refined, based on:

- the quality of the evidence base;
- applicability to supported living care services;
- existing use within the local clinical commissioning groups; and
- relevance to persons with a learning disability residing at home.

The real-world pilot phase was conducted over a three-month period between January and March 2022. This period coincided with a peak of respiratory infections from COVID-19. Workforce pressures led to a reduction in the number of participating supported living providers from thirteen to six. Furthermore, the core project team decided to put a hold on the primary care element of the testing phase.

Activity during the testing phase included:

- Gaining consent from people with a learning disability to participate in the pilot.
- Developing an Easy Read guide about the project for people with a learning disability.
- Providing training to approximately 100 support provider staff on the deterioration tools and quality improvement processes.
- Agreeing with providers which tool they would like to use.
- Conducting surveys for partners involved in the pilot: clinicians, commissioners, and families/carers.
- Developing a safety cross for use by support providers to capture health escalation daily.

- Semi-structured face-to-face interviews with support providers.
- Interviewing GPs and practice receptionists to gain understanding of existing methodologies, areas for improvement, existing pinch points and examples of good practice.

Training

Training sessions via virtual webinars were provided to supported care providers and clinical staff. The training was focused on education around the use of deterioration tools and quality improvement processes, including the safety cross. The training was further supplemented with additional resources offered including regular drop-in sessions, documentation around the fundamentals of PDSA and quality improvement, and the Sonia Sparkles' booklet: *An Introduction to the Fundamentals of Quality Improvement*.

Quality improvement processes

As illustrated in the flow diagram in figure 3, the programme took a quality improvement (QI) approach to collect measures across three domains:

- Process measures
- Outcome measures
- Balancing measures

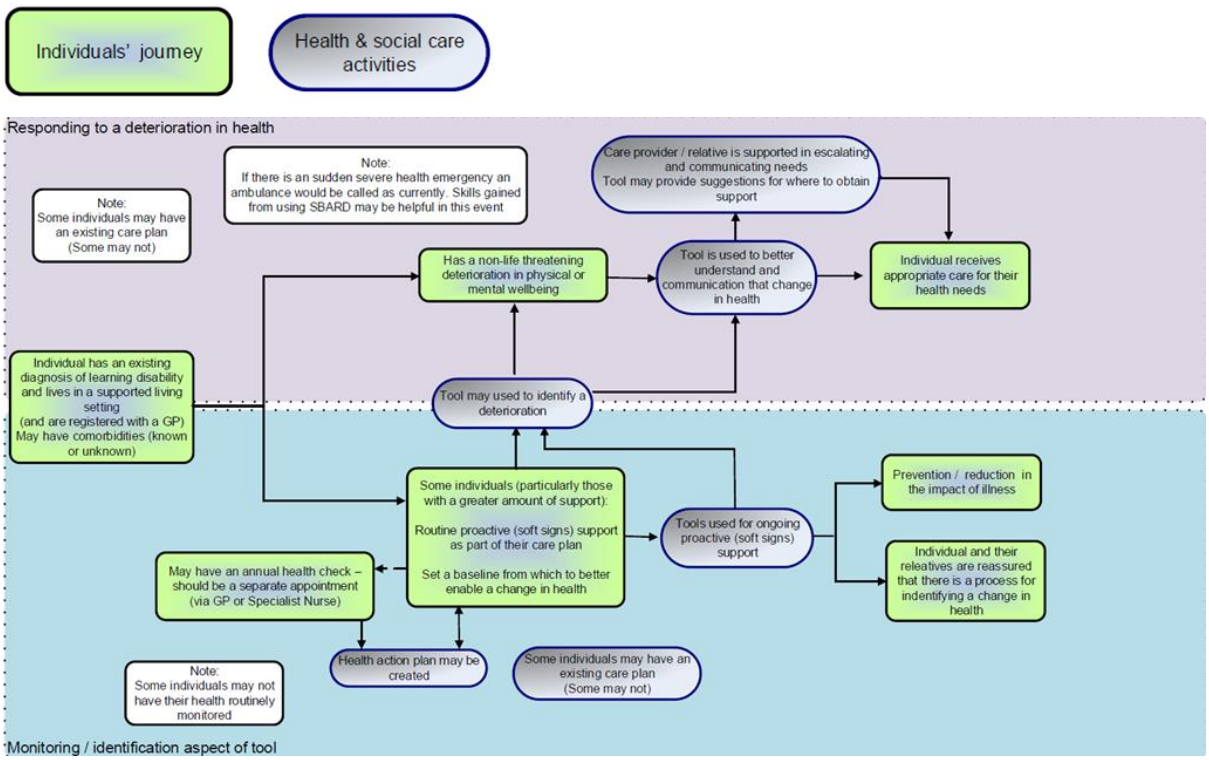

Figure 3: Programme action – logic model linked to evaluation

Safety crosses

The programme experienced challenges with data capture including:

- the short testing period of the programme;
- the requirement to set up data sharing agreements; and
- data being held by multiple organisations, restricting the ability to capture health outcomes within the pilot project.

To support measurement of the learning processes and change management a 'safety cross' tool was developed. This simple tool captured deterioration events (using a red, amber, green score) and the responses of carers over the time of the pilot phase. As no existing safety cross for supported living services was identified, a specific tool and associated training was developed during the programme.

The cross was used to:

- Provide data to measure the impact of using the soft signs tools and SBARD.
- Encourage early detection of issues by providing a visual tool to help staff record events and their responses.
- Identify patterns of concern which may require further investigation or further training support.
- Engage providers to increase measurement of their quality improvement journey.
- Capture information about escalation experience.
- Understand the methodology supporting deterioration detection, including appropriate use, staff confidence and responses from healthcare.

In order to maintain consistency and allow for any limitations in staff's understanding of the tools, it was suggested that team leaders input the safety cross data after discussion with the team. A feedback process to reinforce training was also implemented.

Semi-structured interviews

Supported living providers

Supported living service providers who were part of the pilot participated in two rounds of semi-structured interviews. These interviews were conducted to explore:

- Challenges faced in the identification and escalation of deterioration.
- Examples of good practice, learnings, processes, and administrative systems.
- Capacity, capability, and experiences in quality improvement.
- Co-designing of solutions.
- How practice had altered.
- How quality improvement capabilities had changed.

Primary care

Semi-structured interviews

A total of ten GPs and four reception staff were interviewed as part of an amended approach to the testing phase. This represented ten practices, with 70% being urban and 30% rural. Two of the clinicians were learning disability clinical leads within their practice. These interviews were conducted to explore:

- Understanding of LeDeR recommendations, deterioration tools and opportunities for further education.
- Examples of good practice, processes and administrative systems.
- Challenges faced by clinical teams when receiving concerns about individuals with learning disabilities.
- Existing methodologies which may impact on implementation of deterioration tools.

4. Learning

Learning from supported living providers

Testing tools and quality improvement

Polls undertaken as a part of training sessions found that whilst most carers were unaware of the soft signs terminology, in the main carers felt aware of when things weren't right with the individuals that they supported. Carers reported facing challenges when escalating concerns, as well as lacking clarity around appropriate routes and channels of escalation.

Feedback surrounding the format of the deterioration detection tools given to the provider organisations included:

- Need to be concise, easy to use and clearly formatted.
- Person-centred approach is important.
- Prompts are helpful.
- Should not be overly lengthy to complete.
- Extra training needed if physiological observations are needed.
- Should avoid duplicating existing records.
- Easy Read formats were welcomed overall by staff and people in supported living, although this format may be less appropriate for some individuals with mild learning disabilities and additional co-morbidities such as autism or behaviours which challenge, requiring alternative styles, for example, the 'Sonia Sparkle' resources.

'Well-designed and was useful for reference, and included prompts to aid completion.'

'Clear, person-centred, well mapped out and easy to use,' but, 'Lengthy and therefore unsuitable for completion unless by a single carer over a period of time.'

'Lengthy and poorly laid out, and again reliant on carers being trained in the NEWS approach, as was another tool on the pilot.'

It was recognised that signs of deterioration are more easily recognised by support workers who have consistent relationships with individuals. Deterioration detection can be more challenging for agency and short-term staff. The introduction of tools which give structure to the recording and escalation of concerns were positively received and may help reduce this variation.

Providers acknowledged the challenges on healthcare and felt that by introducing deterioration detection tools to improve consistency and quality of care, this could ensure appropriate use of the wider system only when it is needed.

‘It about building up a relationship so that the GPs can trust that when we ring up, we are not making a fuss and we have done our pre checks.’

Supporting effective communication between care and clinical teams was also thought important as a vital part of the escalation process and the use of SBARD tools have been welcomed by support providers.

‘[Incident described] is an example of when you get frustrated because they simply don’t believe us. Our community nurse is supportive and [they] often seems to act as a go between.’

‘To be listened to is a big issue. Our staff know these individuals well and when they notice that something is not right; they want health professionals to take them seriously.’

Interviewees suggested that individuals with greater vulnerabilities needed to be met by a better response from some NHS professionals, by lowering the bar for intervention and by adopting a precautionary approach. Improvements in the care system such as supporting structured communication by care staff could help do this without overwhelming the healthcare system. Social care provider systems must ensure that effort is not wasted or duplicated when contacting healthcare. Training on the use of deterioration tools and quality improvement techniques is essential for change management.

‘Note-taking on the actions taken could be improved, as there may be multiple people contacting health services, and there need to be clear messages about actions taken and agreed.’

‘Leadership that promotes autonomy in staff to act when they think something is not right. Instilling in staff that they need to be able to justify their decision and to act, [but] you will never be in trouble for calling a GP.’

The need to deliver greater health care support via social care staff risks medicalising home environments by prioritising medical needs over those for wellbeing, social interactions, autonomy and side-lining important elements of care itself.

Defining where caring to support wellbeing ends and acting to treat illness begins is challenging, but in some cases it was suggested that resources for closer physical or mental health monitoring were not accounted for in the ‘care package’ originally agreed for some individuals. With increasing acknowledgement of the role of carers in health monitoring, there needs to be a realistic assessment of the necessary time and skills required, how this

affects overall care delivery, the cost implications, and how these potential changes can be covered, including through possible efficiencies.

> 'The placement was very difficult. Part of the problem was because the initial assessment was incorrect, and insufficient resources were allocated, which impacted on the care provided. We tried to manage the situation to the best of our ability. The service (and service user) wasn't safe, nor were staff. Subsequently, we had to keep on challenging for additional resources.'

System-level proactive care

Interviewees spoke about how the configuration of health and social care systems can impact the care received by people with learning difficulties living at home or in residential settings.

In areas where there has been a long-standing relationship with local GPs, support providers reported excellent and prompt response when called upon and as such had very few issues with escalating concerns.

> 'We have a really good relationship with a practice in [city name]. They do a weekly ward round, a couple of hours every week, and go through every patient, review medication, and talk to the person and the manager. It enables the GP practice to keep in touch with what is happening here.'
>
> 'Some social workers are really proactive and do all their regulatory visits, and some we have not seen since the person has moved in.'

The wider system can enable individualised care by accommodating the needs of people with complex learning and health needs.

> 'Usually very good person-centred service by local dentists. Hospital dental service is available if there are particular requirements, e.g. anaesthesia for certain procedures.'

Individualised care can further lead to involvement of staff with experience and designated responsibility for people with a learning disability can also contributed to improving health and wellbeing.

‘One person has a named district nurse, who was very helpful during the pandemic. She trained the support team to manage the person’s pressure sore. This reduced contacts and the team successfully cured the pressure sore.’

Social care staff had access to a learning disabilities nurse drop-in ‘café’ where staff could share and receive advice and support. It was suggested that there is a lack of acknowledgment and maximisation in how specialist learning disabilities nurse support can support primary and emergency care services by enabling early preventative action.

Access to healthcare can be complex with unclear pathways. Access should be streamlined to ensure individuals received timely care when it was most needed.

‘We think that there should be a flag on GP records that makes a person with a learning disability a priority.’

‘111 is sometimes a difficult service to use, as they have a standard set of questions which are not always relevant.’

It is common for people with a learning disability to experience significant challenges and delays in obtaining non-prescription painkillers without the involvement of a GP. Carers are often expected to be able to support this process, however there is a general unawareness amongst NHS staff that for many carers this is outside of their role and competencies.

‘A client needed a prescription for paracetamol. The surgery didn’t call back, so eventually we called 111. We explained we were doing the monitoring, but we just wanted a prescription. They said to send someone to check it out. Someone came. They said, “Their signs are fine, why did you call me?” We explained, “We just need some paracetamol for them.” Something as simple as that, wanting some paracetamol. It should not take a whole day.”

Implementing proactive policies can have positive effects on quality of care, improve outcomes and reduce pressure on the health system. One provider has introduced a policy to guide carers in helping clients access over-the-counter medicines.

> ‘By use of an agreed list of over-the-counter home remedy medicines, care workers can support service users in a timely manner to manage minor ailments on a when required basis for a short, defined period of time.’
>
> *Extract from a locally developed medicines policy document.*

This learning supports findings from previous evaluations carried out by the East Midlands Academic Health Science Network (*Evaluation of a new direct supply and pathway of paracetamol in Lincolnshire Care Homes*).

Working with the wider system also enables proactive care, promoting cooperative ways of working.

> ‘The pharmacist was really excellent – we arranged for them to come out to us and do the booster and flu jabs.’

Additional training for NHS staff in dealing with people with a learning disability, and the care sector more generally, would be welcome to ensure that the system was consistently responsive to different individual needs and resulting complexity.

> ‘The receptionist knows the individuals and makes adjustments, such as finding a seat in a quiet place, making appointments at end of day so there is more time.’

Record-keeping

An important area of interplay between prevention and escalation of illness was seen in the administrative and record keeping systems available to carers. Optimal systems enabled consistent monitoring and documentation of baseline health and wellbeing of each individual. This supported less experienced staff in recognising change, ensured care was delivered as planned, and made important information available to carers who might be changing over time.

Examples of processes to support prevention of illness included:

- Health Action Plans to address any cause for concern
- Care planning
- Monitoring records to ensure routine vaccinations, screening and health checks are completed

Digital systems allow important information to be readily available by multiple members of the team, irrespective of their location. Information can be updated and shared with remote

supervisory staff. Improved continuity of care can support the identification of concerns. Up-to-date digital records can also be easily shared with health care should the need arise.

> 'If there is an emergency and someone needs to go to hospital, they take their hospital passport with them. This gives the consultant and staff some insights: when the person last visited hospital, what happened, what treatment was given, what meds etc. The records have a five-year history, so clinical people can see the detail and the background. When a record is updated, we print out a new copy.'

Many of the tools provided during the pilot were incorporated into existing record systems.

> 'We are using the soft signs tool in the meds folders, […] so that staff can record straight away.'

Robust administration systems ensure routine events such as health checks, optician, podiatry and other specialist appointments are not missed.

> 'Social care staff need to chase appointments for annual health checks – they are not automatically invited by GPs.'

Learning from primary care

Reception staff process

The process for when a carer contacts a GP surgery was discussed with all reception staff and highlighted several areas of good practice and areas which may present risks. There are as follows:

- Most individuals with a learning disability have a flag on their record to indicate this.
- There is a high variability in the types of flags which can make it challenging to recognise.
- Some examples of flags are: symbols, notes on the front screen and pop-up messages.
- The most valuable flags are those which have clear instructions for the reception staff to follow.
- Some staff use prior knowledge and recognise individuals or their carers. This can be difficult especially when both carer and reception staff regularly change.
- If there is no flag on the system, reception staff would not typically ask if an individual has a learning disability.

- Carers do not usually mention if an individual has a learning disability when they contact surgeries.
- If there are no appointments available and a carer communicates a concern, receptionists would typically speak to a doctor. If a concern is not communicated, they may ask to call back the following day.
- Valuable information from carers at the initial point of contact by 'phone may not be communicated to the GP as receptionists do not usually write in the patient record.

Clinical staff escalation process

The process for when a GP consults with a carer on behalf of an individual with learning disabilities was discussed with all clinical staff and highlighted several areas of good practice and areas which may present risks. All GPs were consistent in their processes and are as follows:

- Not all clinicians will have pre-existing knowledge of the individual.
- Information in the medical record is looked at to help build a picture of the individual including previous history and consultations, medications and demographics.
- Important flags, warnings and/or coded entries are looked at in the medical record.
- Important information and coded entries can become inactive, hidden, may be inaccurate or sometimes are not added correctly to the patient record.
- Clinical systems can be different in how they display information.
- Clinicians will always try to speak to the individual directly if possible.
- If discussed with a carer, the consultation is marked as "third party consultation" and the name of the carer is usually documented.
- In scenarios where the name is not documented, an entry stating 'Carer present' or 'spoke to carer' is made.
- It is harder to detect if an individual has a learning disability on a telephone consultation.
- Carers do not always mention that the individual has a learning disability.
- Where it is not immediately clear that an individual has a learning disability, it usually becomes apparent as the consultation continues.
- Most documentation is done in free text.
- There are no learning disability specific templates which can support the consultation.

LeDeR report awareness

Clinical staff were aware that individuals with a learning disability have poorer health outcomes and higher mortality rates from reversible illnesses. They were also all aware that individuals with a learning disability had poorer outcomes from COVID-19. However, only the two learning disability clinical leads were aware of the LeDeR report and its findings/recommendations.

None of the reception staff were aware of the LeDeR report or its findings, however all the staff were aware that individuals with a learning disability may be at higher risk of deterioration, and as such are aware that these individuals should usually be prioritised.

Deterioration tools awareness

None of the interviewees were aware of the deterioration tools that were being used in the testing phase. Clinical staff were loosely aware of soft signs and were aware of SBARD communication. It was felt that to feel confident with using a deterioration tool, they would want more confidence in understanding its origin, if the tool had been validated and clinically assessed, and more education about how and when it might be used.

All clinicians felt that using soft signs could be a useful mechanism to empower non-clinical staff to detect deterioration and would welcome tools to support carers. There were some concerns that some individuals with a learning disability do not present with typical symptoms, and there could be a risk that something subtle may be missed if it is not included in the tool.

Clinicians found that they subconsciously use SBARD communication to help extract information from carers. All clinicians would welcome carers being trained and using SBARD as they feel that it would benefit the consultation. Clinicians would also not have any hesitancy in sharing what their decision was, so that it could be captured by the carer, assuming appropriate consent was in place. Clinicians felt that SBARD would help carers feel listened to and supported. This in turn may reduce frequent calls and carer anxiety.

> ‘I would love it if a carer told me that they had used a tool that suggests there is a concern. I would also be more than happy for the carer to follow SBARD communication if it helps get their concerns across.’

Clinicians felt that having multiple tools may be a barrier to implementation. Ideally, using one tool across a system could ensure scalability, simplify training and achieve tangible efficiencies.

Experiences in detecting deterioration

Clinical and reception staff were asked to reflect on experiences where they felt that the escalation of deterioration from a carer had gone well, and where they had felt it could be better.

Effective and clear communication is essential in ensuring that concern is conveyed from carer to healthcare professionals. GPs felt this is the most helpful way to support an individual. Having a structure to share concerns would be helpful for GPs. Speaking with a more confident and experience carer can help a consultation run smoothly, whereas less confident carers can take longer to elicit the concerns. This can slow the consultation, which can add additional pressure to the GP and longer waits for other patients.

‘Most experienced carers are able to tell you why they are worried, and can communicate this to you clearly. Some less experienced carers don’t appear as confident talking to GPs and this can make the consultation more challenging, as it is difficult to find out what the problem may be.’

GPs recognised that they are often working under extreme pressures, with short consulting times per patient (10-15 minutes per consultation). This can mean that getting information succinctly and clearly can help the flow of the consultation. GPs mentioned that some carers will come with notes, especially if they are worried they might miss something. GPs don’t mind this approach and find it can be quite positive in supporting the individual.

‘Some individuals are not able to communicate their symptoms, so we rely on the carer to help understand what might be wrong. Making assumptions can be dangerous, and we need to ensure that carers feel empowered to tell us what they feel is wrong.’

Receptionists acknowledged that often long waits on the phone can frustrate carers who may be busy or on tight schedule. Receptionists felt that whilst it is understandable that a carer may be frustrated, this can often lead to less relevant information coming through to them. Often, they don’t get the information that might be helpful. The clearer the information, the easier and quicker it is to help the patient.

‘When people finally get through to us, you can often hear the frustration in their voice. The last thing they want to do is get asked questions, they just want to be booked in for an appointment with the doctor.’

‘It would be useful if the carer would tell us, “Mr X has a learning disability. I am worried about his cough, and I think I need to speak to a doctor.” Instead, we often get, “Mr X is unwell and needs a doctor.” The lack of clear information can make it difficult to help get the individual the help they need.’

One of the practices tried a priority line for high-risk patients, however found that during a pilot it was regularly misused for non-urgent issues by other patients, so they had to withdraw it. Practices found that, despite having a recorded message saying that this number is only for high-risk patients, others would still use it, and then get angry when they were turned away. This clarifies the importance of stating ‘high-risk’ criteria.

Continuity of care can be crucial in ensuring that deterioration is dealt with appropriately. Interviewees felt that when the care team and clinical team knew the individual well, outcomes were generally more positive. They felt that when there were gaps in continuity, there was a risk that the outcome could be poor.

‘‘I find that when family members contact us, or often an experienced carer who knows the individual well, the dynamics of the consultation really do change. These carers know the patient well, they are able to clearly tell us that something is not right, and often explain why they think something is not right. It is really challenging to try and extract that information from someone who doesn’t know the patient at all.’

Conversely, some of the most frustrating consultations for GPs are when they receive second-hand information from a carer who doesn’t know the individual well, and have often received a poor handover, or none. These scenarios can be frustrating for clinicians, as they feel it is difficult to make an assessment with minimal information. GPs would appreciate effective handovers amongst carers to ensure they can get all the information necessary to help make an assessment.

‘Sometimes you phone a carer and all they tell you is, “Mr X is unwell and needs an appointment.” When you try to get more information, all they tell you is, “I’m not sure, I was just handed over that he is unwell and needs an appointment.”

As part of a normal consultation, the GP would give a carer a ‘safety net’, for which is usually a list of things to look out for. GPs found that supporting this with written documentation can be very valuable, as it can be passed on accurately between staff.

‘I sometimes worry that if carers don’t hand over information about their concerns when a shift changes, would they handover what to do if things go wrong?’

‘I always try to give written guidance to carers to outline what to do if things change.’

Clinicians also find that there are better outcomes when there is continuity of care within the clinical team. One practice has set up a process that if there is a concern for a high-risk patient with a learning disability, a follow-up appointment is automatically made with the same clinician within an appropriate timeframe. This ensures that the same doctor addresses any outstanding blood tests, results, or concerns. The practice find that this approach saves time, as typically a new doctor would have to go through all the notes to understand what the problem is, and there is a risk something might be missed.

A high churn rate of clinicians can make continuity of care challenging for many practices, especially those that are heavily reliant on locum doctors. Learnings from this particular practice, however, were very positive, and it was felt this system could be replicated in other practices to ensure continuity of care for high-risk patients.

‘Sometimes medical notes are not always comprehensive, and this can lead to things being missed. Continuity is definitely key.’

Some practices find it valuable to have named clinicians for certain patients. As the clinician knows the patient well, they are able to recognise deviation from the baseline. However, it is very rare that GPs work five days a week, so there may be times that the named GP is unavailable. To combat this, the practice tried a buddy system with two named clinicians for the higher risk patients, with positive results. This system ensures that there is always at least one clinician available who is aware of the patient.

‘We regularly discuss patients who may be higher risk amongst our team, and in our buddy system. It makes sure that at least one doctor is around who is aware of the patient’s current needs or concerns.’

Receptionists do not typically create entries in the patient record, however there was recognition that perhaps some of the information captured from the initial phone call could be valuable for the doctor. It was not entirely clear why receptionists do not document in the notes. Most clinicians felt that it would be outside of the remit of a receptionist to document something clinical in the notes, as they are not typically clinically trained, and there is a risk that something may get misinterpreted. They would prefer to take the history from the carer themselves. However, this can lead to challenges especially if the carer who made the initial call is unavailable or has finished their shift.

Clinicians recognised the pressures on the care providers and understand that there are low rates of retention and a high churn rate of staff. They also appreciated that the job can be highly stressful, so try to do their best to support carers, where they can. There was also recognition that in depth knowledge of carer roles is somewhat limited, and to tackle this, a collaborative individual-centred approach can be effective.

One of the practices has worked very closely with a local supported living home to deal with challenges, setting up regular touch points and ‘ward rounds’. They felt that this had built confidence and trust amongst clinical and care teams.

‘Collaboration is essential as we build pathways to support a person as a whole, not just as a patient. We can only do this if we work collaboratively with social care and share our strengths and frustrations.’

It was felt that sometimes a lack of experience or lack of prior knowledge about an individual can lead to potential signs or features of deterioration being missed by a carer, which in turn does not get escalated. This can be especially challenging in individuals with a learning disability, as they often do not have textbook changes. Clinicians would welcome carers being supported with further training or tools to help identify deterioration. It was felt that clinicians could also be more proactive in supporting this change, by sharing signs of potential deterioration to look out for.

> 'Carers are not always confident in recognising potential deterioration.'
>
> 'Some of our systems can be improved, we need to be more proactive and less reactive. We need to empower individuals on how things might look when things might be going wrong.'

Overall, all interviewees felt that there was room for improvement in improving the process of deterioration detection and would welcome tools to support this process. It was noted that GP surgeries are all structured different, and as such adoption of good practice could pose significant challenges. Despite this it was felt that all new changes should be collaborative and include both health and social care, with the individual at the heart of any new change.

Annual reviews

Individuals with a learning disability should have annual health checks, which can help with empowerment for both individuals and their carers. Health Action Plans includes things beyond the annual health check, such as escalation of care and what should be done if something goes wrong. Comments from primary care were made that carers don't always refer to the health action plans, and this could be improved.

Pandemic pressures resulted in virtual annual health checks and health action plans being performed remotely utilising technology. Whilst the project heard about concerns regarding the quality and robustness of reviews undertaken during the pandemic, practices reflected on how the ability to perform these assessments remotely resulted in higher numbers completed. All participants within the pilot had their Annual Health Check and Health Action Plan completed, however it was noted that often individuals do not attend health reviews. This can impact on already limited clinical appointments.

Training

All the clinical staff felt that they had good awareness of the clinical needs and challenges faced when assessing an individual with a learning disability. Clinical staff felt that consulting with an individual with learning disabilities can be challenging, especially in individuals with complex needs or communication issues. They felt more confident when a care giver or family member is present who has prior knowledge of the individual.

There was a general feeling that training around learning disabilities could be improved. Clinicians felt that there is a broad range of learning disabilities, so it is important that high quality training is regularly made available. Much of the training available in relation to individuals with a learning disability is either based on the Annual Health Check or medication reviews (STOMP). Whilst this is welcomed, it is not always applicable to supporting with deterioration detection.

Clinicians welcomed the idea of learning from individuals with lived experience but felt that busy workloads can make it difficult to attend these types of educational meetings. They felt that pre-recorded sessions and e-learning modules would be a flexible way to engage with training. All GPs felt that learnings from case studies, audits and reviews is a powerful way to implement change and would welcome greater awareness and sharing of the LeDeR report.

Reception staff generally felt less confident in their awareness of the clinical needs and challenges faced when dealing with a carer or individual with a learning disability, and all felt it could be improved.

Reception staff felt that there is limited training around learning disabilities. Much of their awareness came from experience on the job. All reception staff would welcome learning disability training at their induction, and periodic refresher training, in line with other mandatory training.

All interviewees would welcome training on deterioration detection tools and felt this would be essential for successful uptake in primary care.

Safety cross

In total, twenty-four safety crosses were received from six providers. The data collection period was over three months from January to March 2022, three (50%) of the providers shared data for three months and three (50%) shared two months' data.

Completion of the safety crosses was inconsistent, with some data not being completed or lack of clarity of the data presented. Supporting documentation was also variable and inconsistent, with partial completion of notes and documentation of where SBARD had been used. This was compounded as data recorded on the paper version of the tool was at times difficult to interpret.

This made it difficult to assess the impact of this pilot using this data, due in part to the amount of incomplete and missing data, the short data collection window and that some single forms recorded events for an unknown number of residents.

In the three-month testing phase, providers were iterating the tool and learning how to incorporate into their processes, leading to inevitable data quality issues. It was difficult to assess whether providers were completing more accurately towards the end of the testing phase.

One participant suggested that individuals could use the safety crosses themselves with suitable support, and that this could improve their self-care skills and be adapted to record specific events or aspects of health, such as alcohol use, mood, diet or as a 'falls tracker'.

Integrated Care Systems

The programme has resulted in improved awareness of issues relating to deterioration for people with a learning disability in supported living settings. In some of the pilot areas, it has led to closer communication between providers of supported living services and the local LeDeR programme, with expressed intentions and plans to continue to explore how collaborative improvements can be made and sustained at integrated care system level. In at least one area, the actions from the pilot project will sit under the health inequalities work stream, and it will also inform commissioning intentions/specification on the supported living framework.

There was a keen appetite from all participants to receive the findings from this report, as well as be acquainted with what next steps from the National LeDeR and NHSEI teams would indicate for their respective areas. Both providers and commissioners indicated that they would value the opportunity to extend the implementation of the programme.

The programme greatly benefited from the collaboration between the AHSN Patient Safety Collaboratives (PSC) and Association of Directors of Adult Social Services (ADASS) health and social care colleagues. Their respective knowledge and understanding of the infrastructural landscapes of both organisations, as well as active engagement of stakeholder bodies, lead to clear and unbiased communication between all parties.

There were limitations in the ability to access robust outcome measures to identify the overall benefits for individuals with a learning disability, as information systems were not interoperable and the information was not collected in a way that was synchronised between health and social care.

5. Emerging recommendations

Further testing

The overarching recommendation is to build on the initial learnings in a larger-scale programme across a wider geography. Data captured from the initial pilot was drawn from a small sample of providers and clinical teams, who volunteered to be involved in the programme. There is a risk that learnings may not generalise across wider cohorts, and with this in mind, testing over a wider footprint will enable identification of tangible efficiencies.

Care needs to be given to scaling up processes, collaboration and measuring a variety of outcomes. Co-production and a multi-organisational approach to further testing is essential to ensure an inclusive approach to quality improvement.

More work is required to test deterioration tools and refine them further to suit the needs of individuals with learning disabilities. Testing of tools which may support self-identification of deterioration should also be explored. Further assessment is required to understand how these tools impact delivery of healthcare, and an exploration into the effect on clinical outcomes.

It is important to build on initial learnings from primary care to understand how healthcare processes can be further adapted to support individuals with learning disabilities. Testing of best practices should be explored with the aim to develop primary care toolkits for wider dissemination across healthcare settings.

An analysis of the system efficiencies, cost savings, admission avoidances and impact on health and social care resources should be built into the next phase from the outset.

Deterioration detection tools

Utilising deterioration detection tools is recommended as these tools were particularly useful in supporting staff who do not know an individual well. Furthermore, the tools give structure to communicating concerns which improve carer confidence as well as potentially improving workflow processes for a clinician. It is recommended that deterioration detection tools even in their current format can be beneficial for an individual with learning disabilities.

More work is however needed to understand how the tools can be enhanced and their impact on clinical outcomes.

Digital tools and development of apps and internet-based solutions should be considered.

Training

Training to support knowledge and awareness of the needs and associated reasonable adjustment required for people with a learning disability is required. Further education around soft signs, SBARD, PDSA cycle, quality improvement methodology and the use of deterioration detection tools is also required within both health and social care settings.

Developing shared reflective learning sessions to improve communication, relationships and collaboration between health and social care. Enhancing the relationship between health and social care will support social care staff being viewed as equal partners in the detection of deterioration.

Wider understanding and participation in quality improvement processes to enable both health and social care providers to continuously collaborate and improve the quality of care and outcomes. This should include training.

Capacity and availability of resources may limit delivery of training for a pressurised workforce.

Service development

Recommendations should be reflected in specifications and contracts to enhance governance, compliance, and appropriate commissioning of services.

Successful implementation within supported living services requires a system-based agreement regarding the escalation of concerns and response. Clear escalation pathways should be developed which are visible and accessible to staff working in social care settings. Systems should be supported in the creation and dissemination of decision support guides, to create awareness about the different service offered, alongside contact details of these relevant bodies.

It is essential that people with a learning disability are properly triaged and identified when referrals to supported living services are made. This is to ensure that providers can provide appropriate support specific to an individual's needs.

Collaborative approaches to improving access to annual health reviews, health action plans and protocols to support access to over-the-counter medication should be considered.

6. Conclusion

Based on the findings from this programme, there is sufficient evidence to warrant further, larger-scale testing with supported living providers and the health and care system which works with them.

Building on the learning, these are some of the considerations that should be taken into account for future pilots:

- Developing further the communications and engagement links across the health and social care system and aligning closely with the national managing deterioration safety improvement programme.
- A formal analysis of efficiencies and savings should be incorporated from the outset, linked to ICS development and planning.
- Incorporate additional skills within the project team, in order to fully quantify the benefits and outcomes for individuals and all parts of the system.
- Adopting a place-based approach will ensure that the project findings can be rolled out swiftly via ICS systems.

To achieve the next stage of maturity, the completion of a set of measures will also be needed that follows the whole process, from initial use of deterioration tool through to the escalation process and response from clinical teams. Without measures of an integrated and interactive system, there is little value in just improving one element of the process.

Caution is needed until we can successfully express and measure the processes taking place and know how reliable they are (or otherwise), and any unintended consequences built into them (balancing measures). These measures should be built into any future programme.

This pilot was limited in its ability to quantify cost savings or to identify specific health outcomes. It would have benefitted from obtaining baseline information, and this will be crucial for future pilots. However, there are challenges to sourcing these data:

- Health and social care information systems are not necessarily aligned in a way that allows data for individuals with a learning disability who live in supported living settings to be extracted.
- Due to data protection and information governance regulation, significant delays would have been experienced when trying to obtain this data by way of setting up data sharing agreements, and then creating and designing a methodology for analysing it appropriately.

This pilot programme has highlighted improvements that we can make for people with a learning disability, which has the potential to have a significant impact on their health outcomes and potentially save lives. It has shown the positive impact of collaborative working amongst multi-organisation teams from across health and social care working together towards a shared common goal.

No one part of the system can achieve change in deterioration management for those living in supported living settings alone. We hope this is the beginning of sustained change that helps reduce health inequality for people with a learning disability.

Acknowledgements

We would like to express heartfelt gratitude to the individuals who have contributed to this pilot. Firstly, the individuals with learning disabilities who consented to be a part of this really important work. Secondly, we would d also like to thank providers of supported living services and primary care who, through really busy and challenging times and schedules, made themselves available to volunteer to be a part of the programme.

We are grateful to colleagues across social care and healthcare who opened their doors, attended steering group and other meetings, and created vital introductions. Most importantly, thanks to the Midlands LD NHSE and LeDeR team who commissioned this programme out of the learning from action, and due to their passionate desire to make a difference – we couldn't have done this without you.

Biographies

Eddie Alder

Programme Delivery Director, East Midlands Academic Health Science Network

Eddie is a Registered Nurse and former Head of Patient Safety at EMAHSN. His role at the EMAHSN is responsible for a range of improvement and innovation programmes.

Eddie has worked extensively in clinical and leadership roles across the NHS for 30 years. Eddies clinical career was largely focused within community services, General Practice, and offender healthcare services, where he developed a professional interest in service improvement to address inequalities in healthcare provision.

Since working at the AHSN Eddie has co-led the national mental health safety improvement programme and is a keen advocate for parity of esteem for people with mental health conditions, learning disability and / or autism.

Dan Hodgkiss

Patient Safety Assistant Programme Manager (West Midlands Academic Health Science Network – Patient Safety Collaborative)

Daniel leads the Deterioration National Improvement Programme for the West Midlands focusing on acutely ill patient deterioration/ implementation of NEWS2 (National Early Warning Score); and the spread and adoption of the Bristol ED Checklist.

Daniel worked previously for Walsall Healthcare NHS Trust from 2014 - 2019 and was the Patient Safety Manager for MLTC and Adult Community, where he investigated serious incidents ensuring Human Factors were an integral aspect of all investigations.

Daniel developed a nationally recognised initiative relating to the management of frequent attenders to A&E who had complex social issues. Daniel embedded Appreciative Inquiry throughout the Trust developing a number of approaches and tools such as Right Cause Analysis, and delivered a workshop at the World Appreciative Inquiry Conference 2019 surrounding the movement to a Safety II culture.

Daniel was part of the 2018 HSJ winning team for the Clinical Governance and Risk Management Award and the Patient Safety Meridian Award in 2019. Daniel has a real passion for developing positive safety cultures in healthcare using Quality Improvement and Appreciative Inquiry approaches whilst ensuring patients are at the heart of the work.

Samson Ifere

Programme Manager, East Midlands Academic Health Science Network

Samson Ifere has worked in various capacities in Health and Social Care from 2008. His passion for working with people with learning disabilities began whilst as a student where he worked as a support worker and through his career has worked in different capacities in the NHS in various senior management roles.

A strong passion for working with people and an acute attention to detail, he employs the principles of project and lean management to deliver financial and economical value without compromising care quality. Commissioned by the East and West Midlands Academic Health Science Network, he served as programme manager for this programme, and has also led on different work streams over the past 2 years.

His core strengths include using programme and project management principles to embed quality improvement

alongside strong data analysis as well as embedding effective working relationships across multidisciplinary and multi-organisational working groups.

Catherine Nolan

Regional Lead – People with Learning Disabilities and Autistic People (West Midlands ADASS)

Catherine has worked for people with a learning disability for over 30 years; beginning in special education, she has worked in the third and public sectors in England and abroad, spanning most aspects of operational services – as a practitioner, manager, and commissioner. She is also a Trustee of an independent advocacy organisation.

Ranjan Ravat

Regional Lead for Learning Disabilities & Autism (East Midlands ADASS)

Ranjan has worked in Adult Social Care for over 25 years covering a breadth of disciplines including domiciliary care, residential care, hospital social work, service transformation, and commissioning.

Prior to this regional role, Ranjan was responsible for setting up a specialist Learning Disabilities Social Work service aligning with the TCP programme in her area. Working with colleagues across health, children's services and SEND, Ranjan has also been instrumental in developing a Transitions strategy pathways in Leicester City.

Her current role provides an interface between NHSE and ADASS and involves supporting the TCP partnerships across the East Midlands to promote collaboration and integration.

Ranjan is also the local Branch Secretary for a national organisation that works with south Asian communities for the relief of hardship , poverty and social inclusion.

Kit Roberts

LeDeR programme reviewer, Telford and Wrekin, and South Birmingham and Solihull

Kit began working in adult education, with people with a learning disability at St Margaret's Hospital, Birmingham in the 1980's. In the 1990's, Kit was the Executive Principal of the Mencap National College, with responsibility for 3 specialist residential colleges of further education.

Later, Kit moved to the Learning and Skills Council as national programme manager for Inclusive Learning, and subsequently, Director of Equality and Diversity.

Finally, Kit worked in several roles for Telford and Wrekin Council including joint commissioner for learning disability, business manager and lead for Building Better Care.

After retirement, Kit returned to lead on Transforming Care across Shropshire and Telford and then became a reviewer for the LeDeR programme reviewing deaths in both Telford and Wrekin and South Birmingham and Solihull.

Chris Sholl

West Midlands ADASS

Chris began working with children with learning disabilities as a volunteer when she was on a gap year. She was hooked, so decided to train as a social worker rather than follow her original plans.

Since this time, she has worked with children and adults who have a learning disability, and their families in a variety of roles for over 30 years across local authorities and the NHS.

Chris has also worked independently for many years, leading a number of local, regional and national projects. She is passionate about ensuring that people with a learning disability and their families are central to her work, so that their voices and views are heard.

She was an investigator with the Confidential Inquiry into Premature Deaths of People with Learning Disabilities and is an independent professional adviser in Care and Treatment reviews.

She helps to develop Life Plans for people leaving secure hospitals and facilitated the West Midlands Family Carer

Network for many years on behalf of the National Valuing Families Forum.

Gurnak Singh Dosanjh

GP Clinical Fellow, East Midlands Academic Health Science Network

Gurnak is an NHS General Practitioner and is passionate about digital innovation and reducing health inequalities. Gurnak is highly experienced in the transformation of clinical pathways, having been involved in numerous projects across the UK. These have included digital support for long-term conditions management, creation of virtual wards and implementing Proactive Care at Home pathways. He is also designate ICS clinical lead for urgent care outflow and virtual wards in Leicester, Leicestershire and Rutland.

Gurnak is keen to promote safe digital innovation whilst ensuring that this does not widen health inequalities. He is a keen advocate of patient empowerment and ensuring that patients remain at the very centre of any innovation and transformation.

Chris Wall

Project Manager, Service Improvement, Quality & Practice, Adult Social Care & Public Health, Nottinghamshire County Council

Chris has worked on a variety of Adult Social Care (ASC) projects with colleagues across strategic commissioning, service transformation and improvement, Nottinghamshire CCGs, East Midlands ADASS, and other local authorities in the region. Projects include:

- Developing the LeDeR pilot for East Midlands ADASS.
- Improving processes for the Shared Lives scheme.
- Developing a new day opportunities strategy with people who use services.
- Connecting the local ASC recruitment campaign with the national DHSC campaign.

Chris has also worked on other cross-departmental projects within the council. She is currently working on the new ASC quality framework in readiness for future Care Quality Commission inspections.