

# Clive's Way: A Conscience Manual

Further information and guidance following the Clive Treacey Independent Review





## Foreword

Clive was a much-loved family member and a man who had clear aspirations about his adult life: a place to live in the community that was close to family, and a job, ideally in a garden/horticulture setting. Clive never realised this dream and he was caught in a system that could not and did not meet his needs and that lessened his chances of ever finding a place to call home.

Passed from setting to setting, Clive ended up being detained under the Mental Health Act (MHA) for a decade. There was a lack of National Institute for Health and Care Excellence (NICE)-compliant good quality care and treatment for his presenting needs, and in some cases, although the minimum standards were met, they were insufficient to meet Clive's needs. He gained a reputation for being complex and challenging, and someone for whom a community setting was not properly considered until the last years of his life. When it was, there were financial and systemic barriers that thwarted these attempts and he remained incarcerated in settings that were poorly equipped to meet his needs, in the last of which he tragically died.

Clive's family supported him at every step along his journey. They fought for Clive, for the life that they knew he wanted and to which he had a fundamental right. They raised their concerns loudly, directly to the services, through complaints and safeguarding processes – but they were rarely listened to. Towards the end of Clive's life, they had a strong sense that he was going to die and still their voices were not heeded. After Clive died, his family had to fight for an inquest and then fight again for an independent review in line with the principles of LeDeR methodology. This condemned them to further trauma and to living with many unanswered questions. Together with the loss of a loved family member, this has also had a profound and detrimental impact on their lives.

*Clive Treacey Independent Review*

[Clive-Treacey-Independent-Review-Final-Report-9.12.21.pdf \(england.nhs.uk\)](https://www.england.nhs.uk/02021/02021-clive-treacey-independent-review-final-report-9.12.21.pdf)

NHS England Midlands commissioned an independent review and, from the outset, was committed to ensuring that the outcome of the independent review and its recommendations were acted on. The publication of Clive's review in December 2021 was not the end of a process but the beginning of an extensive programme of work.

Some of this work and other good practice is set out in this document which has been written as a Conscience Manual describing how to do things **Clive's Way**. It has come from the Conscience Group (described on page 10) which came together to support the taking up of the recommendations, appealing to people's hearts and minds. The definition of conscience is 'a moral sense of right and wrong, viewed as acting as a guide to one's behaviour', so this Conscience Manual – Clive's Way is appealing for people to be driven by a sense of what it is right to do after hearing Clive's story.

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## Introduction from Beverley Dawkins (Independent Chair of the Clive Treacey Review)

Following the concerns raised by Clive Treacey's family about the events that led up to his death in January 2017, a review was commissioned by NHSE Midlands in July 2020 and published in December 2021. The review makes 52 recommendations based on 10 findings. Some key points are highlighted below:

- Clive's death was 'potentially avoidable'
- There were multiple system-wide failures in delivering his care and treatment that together placed Clive at higher risk of sudden death
- Clive should not have spent so many years of his life detained in specialist hospitals and that there were extended periods where he experienced an unacceptably poor quality of life and where he was not kept safe from harm

This conscience manual reflects on the impact of Clive's review, what has been achieved so far and progress on the many challenges ahead.

When families fight for many years to achieve justice for their loved family members and hope that sharing their stories will result in a legacy of change for others, they are too often disappointed. People working in services grow weary of hearing yet another distressing tale of loss and service failure and sometimes focus their efforts on defending and denying that things have gone so badly wrong. But something rather different happened here, a way of working evolved that has built a strong partnership between Clive's family and the NHSE Midlands team to drive forward the implementation of the recommendations. This partnership was built on a shared commitment to integrity, honesty, and transparency. I cannot tell you that there were not a few bumps in the road, but they were overcome by good communication and learning and driven by the common purpose of making what happened to Clive matter. This conscience manual and update report is called '**Clive's way**', for despite all that happened to Clive on his life journey he never gave up and was described as '*the master of positivity*'. I hope that when you read this you will celebrate the actions that have been taken in his name and add your own energy to making a difference.

## Why the Review was so important to Clive's family - Elaine Clarke (Clive's sister)

***'Forget it now Elaine. Tomorrow is another day'***

*Clive Treacey*

Before you read on and especially if you have not had the chance to meet Clive through his slide show before, can I ask you to please take a moment to watch it [here](#). That's Clive, my funny, artistic, sporty and brave brother. He is our family's central heartbeat, and he remains so to this day. Clive always lived with pride, courage, strength, ambition and sheer determination. I knew that I needed to move forward in the same spirit after his death.

***'Clive's loss shattered our family..... We did not expect to have to fight to get his death acknowledged or spend years demanding a review that would recognise the failures that we knew had contributed to his premature death'***

*Elaine Clarke*

It was enough to leave a family bitter and angry for the rest of their lives, but that is not the Treacey way and it was certainly not Clive's way. His incredible positivity carried us through until we got an agreement for the independent review to take place. There is nothing easy about having to re-live the worst events of your life, remember all the things that contributed to the awful quality of life Clive so often experienced or the distressing events that ultimately led to his death. We went through that because what happened to Clive mattered, not only to us but everyone involved in supporting and caring for people like him.

***'How are they ever going to be able to change anything if you don't let them try'***

*Mark Clarke, my husband*

This single statement marked a turning point for me. What many people will not know was that early in the course of the review my husband and I learned that he had terminal cancer. My Mark was a quiet but wise man. Married for 36 years, he had been alongside me during Clive's life and after his death and was insistent that everything carried on as planned, including Clive's review. Mark was there for the highs and lows and there with these words of real wisdom when I became angry or frustrated with people who did not seem to take the actions or make the changes that I hoped for.

It's truly impossible to describe the devastating consequences of Clive's loss along with my kind gentle, wise, beloved husband Mark. For me our family, their loss has broken our joyful hearts.

It also highlighted to me that it's not possible to do this any other way but **CLIVE'S WAY**.

***'It's the first time Clive and his family have truly felt listened to and respected. We his family were finally seen as allies, not enemies.'***

*Elaine Clarke*

This alone should never ever be underestimated. It formed a small part of the healing process. We did not expect or consider that would happen, but it did during the course of the review and with all the work that has followed. The impact of being listened to and respected, together with the knowledge that Clive's story was helping to change things has been so important to the whole family.

But there is so much more to be done! For me, the ultimate test is this: if someone like Clive entered the system today how would their journey be different? So, in this manual, we have tried to create some challenges and inspiration to help people think that through.

Join us in creating change by doing it **CLIVE'S WAY**.



## Telling Clive's story

Clive's review aimed to keep Clive and his family front and centre throughout the review process and throughout the writing of the report. As important as sharing the findings and recommendations from the review, was ensuring that those hearing his story came to know something of the man at its heart.

A slide show of Clive's photographs was created, describing things that were important to him such as his family, art, music and sport and some quotes from the people who knew him best. It is set to music using two songs that Clive loved and often sang loudly and proudly! NHS England (Midlands) showed this at the beginning of every presentation and its impact set the tone and the context for talking about his death. A picture in the slide show features Clive attending a case review meeting wearing very large Homer Simpson slippers and putting his feet up on the table to make sure everyone knew he was there, so too did he enter the room and become real for all present.

As important as knowing more about Clive, is the presence of Elaine, his sister. With a combination of a short film of Elaine or, on many occasions Elaine in person, people have been directly able to hear from Elaine about Clive, the impact on his family when he died and her hopes for a changed future for others. **Clive's voice** and that of his family were lost in his journey through services but the strength of his message and that of his family appeared to have an enormous impact on those in the many presentations that followed the review.

It's been difficult to quantify the reach, but NHS England (Midlands) know at least a 1000 people have attended the mix of conferences, Partnership Boards, networks and forums that they have hosted or joined at a national and regional level. The reach has included:

- Partnership Boards with responsibility improvement in care and support for people with a learning disability and autistic people across the Midlands, England regions and nationally
- NHS and Local Authority commissioners of care and support for people with a learning disability and autistic people
- Wide spectrum of professionals responsible for supporting people with epilepsy across the UK
- Social workers and social work practitioners
- Directors of Adult Social Care and other senior managers with responsibility for learning disability and autism services via the ADASS National Policy Network
- Safeguarding leads and safeguarding practitioners
- Occupational Therapists
- Specialist NHS and independent hospitals, and provider collaboratives
- Residential care providers
- Learning disability and autism workforce leads



- Medical examiners
- Clinical leads and professionals engaged in patient safety and learning from deaths
- Epilepsy specialists and professionals supporting epilepsy care

In addition, many Individual Integrated Care Systems (ICSs), Local Authorities and organisations have also hosted their own events to share learning and were given permission to use Clive's slide show. Here are some things people who attended these events had to say about this approach:

***'I am new into my role as a Senior Commissioning Officer, I found Clive's review incredibly sad and moving and it has helped shape my approach to my new role. I am in a fortunate position of being able to come into a role with the learnings from Clive's review playing a formative role in how I approach my work with supporting autistic people and people with a learning disability'.***

***'I think I know many people in a similar situation to Clive. We have much work to do, which needs to start with listening'***

***'Clive was not afforded any opportunity to live his best life possible. With the system dictating, not ensuring Clive was at the centre of all decisions and most importantly not listening to what Clive and his family were repeatedly saying'***

***'As an ICS we have come together and put together an action plan to address any recommendations from the Clive Treacey Review to being all services within the system to work together'***

***'The courage of Clive's family and Elaine are immense. How do we make sure we listen and act on what families say to us? How do we give it the same currency as others?'***

***'Anger, distress, sadness and frustration'***

***'Sad, but familiar'***

***'His death was avoidable. The failure of the system to join up and develop appropriate responses for care and treatment'***

***'Very very sad, but so avoidable'***

## Impact of Clive's Review

***“At the centre of this story is a man who was lost and died in a system that should have become obsolete many years before. His voice was not heard among the many hundreds of other voices and the lives of people like Clive who seem to their families to count for very little indeed.”***

*Beverley Dawkins, Independent Chair*

Could the issues documented in Clive's review be happening to people we are supporting today?

Other scandals of abuse, neglect and premature death continue to appear in the media, each as unacceptable as the last and each demonstrating the shocking lack of progress in enabling people to live with the right support in the community. Clive's report served to underline many issues that are well documented, actions and commitments made for change but that has not been delivered. There remain many other people, who like Clive should not have been admitted to these services in the first place and are still waiting for discharge.

However, Clive's story became a powerful lens through which organisations and professionals were able to sense-check how well existing efforts are making the impact and progress needed. The learning in relation to commissioning and specialist hospitals, where significant investment has been made, is a good example. In other cases, the learning raised in Clive's Review really helped to bring to life and draw attention to known issues that needed greater understanding and visibility, particularly amongst mainstream services - for example, epilepsy, health inequalities, and issues of safety.

The way that Clive's review was conducted, also served to bring to light the inadequacies of many of the reviews that take place after someone has died, some that deeply re-traumatise families, by showing that families can work together with professionals to understand what went wrong and act together to drive change.

Inevitably some issues have had more success than others and the job of engaging in delivering the changes required is far from complete. But alongside the things that need much greater attention to achieve, there are also many areas to highlight where there has been progress.

## Taking forward learning from Clive's Review

*“Following publication, the scale of responsibility felt by NHSE to do justice to Clive's recommendations was significant. Not just because it was something that we owed to Clive and his family, but because of the power that we could see in Clive's story to address the very live systemic issues we were already working hard to tackle.*

*We had no authority to require the many organisations that have engaged with this Review to take on recommendations. We were unsure about how we could reach widely and deeply into health and care systems to get the attention of everyone that needed to hear Clive's story. We knew our approach had to extend beyond the familiar schedule of action plans, no matter how comprehensive they might be”.*

*Hafsha Ali, Midlands and Lancashire Commissioning Support Unit NHSE Midlands*

Significant time and resources have been invested in this process and NHSE Midlands is to be commended for their commitment to designing the programme and following up on the recommendations in the review. Before publication, work was already underway to engage stakeholders in the recommendations emerging and potential response to them. There was an overwhelming commitment from all organisations engaged to address the systemic issues raised in the report.

- **Organisations directly involved in Clive's care** were invited to reflect on their practice and went on to develop high-level actions in response to the findings of relevance to them in the report.
- Senior representatives of **national bodies** referenced in recommendations met with NHSE to think through the recommendations and explore opportunities to take these forwards. This included the Care Quality Commission, Royal College of Pathologists, Resuscitation Council, Health Education England and NICE.
- The greatest opportunity for significant and lasting impact sat locally with **health and care systems**. The Report was promoted to all Learning Disability and Autism Programmes across the country and ICSs were invited to draw on the learning and recommendations of Clive's Review to appraise the effectiveness of their improvement programmes and look at where further attention is needed. Embedded within strategic planning for Learning Disability and Autism programmes in 22/23, the learning from Clive's Review was incorporated into the core business of Learning Disability and Autism Programmes in the Midlands.

## 'Kicking the Tyres' – Keeping an eye on progress

***'Thank you. Listening to Clive's story shared by his family always motivates me to influence our local system change. I've tried to embed opportunities like this to stop, listen and reflect as a system on person stories, we can change the future'***  
*Event attendee*

The following sections build on this initial work and set out some information and good practice that together can act as a '**Conscience Manual**' for local systems and communities wanting to work together to improve care and support for people and learn from what happened to Clive and the work that has taken place since then – in effect, doing it **Clive's Way**.

### The Conscience Group

NHSE Midlands set up a group that became known as the '**Clive Treacey Conscience Group**'. This was an important learning point about how Clive's family were to remain involved in the ongoing process. It was unfortunate that the publication was delayed until early December as the Christmas period is typically one of low activity and for Elaine and her family, the early months felt like a long period of time went by when there was insufficient information about activity, impact or progress.

The NHSE Midlands team reported a great deal of activity as they met and negotiated how the recommendations were going to be implemented with the stakeholders, but Clive's family felt excluded. However, the strong relationships developed over the period of the review meant that there could be an open and honest discussion on how to overcome this and change the approach. This resulted in the setting up of 'The Conscience Group' to oversee progress. The Group was purposefully kept small to a membership of six people selected for their passion to drive meaningful improvement. This included:

- Elaine Clarke (Clive's sister),
- Beverley Dawkins (Independent Chair of Clive's review,
- Hafsha Ali (Managing Consultant - Digital Transformation Transforming Care, Midlands and Lancashire Commissioning Support Unit)
- Robert Ferris (Midlands Regional Director for Learning Disability, Autism and SEND),
- Anne- Marie Holder (Deputy Director of NHSE Midlands) and
- Catherine Nolan (West Midlands Association for the Directors of Adult Social Services Regional Lead for people with a learning disability and autistic people).

As this group developed, it became a way of 'kicking the tyres' of the progress and thematically reviewing key recommendations by inviting some of those working on them to report to the Group. The Group was a great vehicle to celebrate successes whilst acting as critical friends. This has now evolved into Elaine acting as a critical friend at the Midlands Learning Disability and Autism Partnership Board and the Midlands Learning Disability and Autism Quality and Health Inequalities Workstream.

NHSE Midlands also discussed with Elaine what she and the family would like to see in the implementation of the Review and how she would like to be involved. Her feedback informed the principles below, which were built into the terms of reference for the Conscience Group.

- Linking of improvements and impact to Clive's review to Clive and his legacy.
- Acknowledgement from organisations that cared for Clive about failings documented by the Review and assurance that improvements have been/ are being made.
- Clear written plans communicating how recommendations will be progressed, by whom and when
- Clive's family are engaged in decisions and developments relating to the outcome of Clive's review

***'For me, the overwhelming power of this group has been in input from Elaine. At every point she was able to bring us back to the central purpose of what is essential about everything we do in the NHS, which is to work for patients and their families and improve outcomes'***

*Ann-Marie Holder, Deputy Medical Director of NHSE Midlands and Conscience Group member*

## Commissioning and Oversight

Clive's report identified that '*organisations responsible for commissioning and monitoring Clive's care did not always place him in settings that could meet his needs and did not sufficiently monitor the quality of care he received. On some occasions, this placed him at risk of harm*'. In response, the Review specifically recommended that '***NHS England (national) should review existing quality standards for the commissioning of care for people with a learning disability, autism or both and consider whether further quality standards need developing or strengthening***'. It was heartening to see that this was one of the very first recommendations to be mobilised in partnership with the National Learning Disability and Autism Programme Team. In addition, the NHS England Midlands Regional Learning Disability and Autism Programme commissioned West Midlands Association for the Directors of Adult Social Services (WM ADASS) who carried out a study with NHS and local authority commissioners of services for people with a learning disability and the autistic population to understand how the consistency of good practice could be improved.

WM ADASS worked with 10 local health and care systems across the Midlands and collected over 20 hours of semi-structured interviews and documentary evidence to better understand the components of good commissioning practice. The study identified a clear gap in the continuous support and development for commissioners, specifically in the support for implementation of policy and practice. A key recommendation was to establish a Midlands Commissioners Community of Practice (CoP) to provide that support and development for commissioners and provide an opportunity to build an evidence-base for commissioning practice through research.

The second phase of this work has been supported successfully by the National and Regional Learning Disability and Autism programmes with the aim to pilot the Community of Practice in 2024/25 and the team are currently looking for NHS and local authority commissioners working together across an Integrated Care System to sign-up for this opportunity.

Furthermore, WM ADASS have worked with commissioners in the past year to better understand the experience of commissioning on the ground and develop and describe a set of Health, Social Care and wider system partnerships, structures and standards which should underpin practice when commissioning services for people with a learning disability and autistic people.

WM ADASS have also worked with Midlands Principal Social Worker Networks, NHSE Midlands, Clive's family and Beverley Dawkins to facilitate a Midlands-wide workshop for social work practitioners so that the findings could be further considered with a view to developing some good practice principles for future practice. This gave social work practitioners the opportunity to consider the findings in the context of the work that they do and to enable meaningful change and improvement. The outcome of this work has culminated in the development of targeted principles to guide social work practice in the Midlands.

## Specialist Hospitals

***'Whilst improving outcomes carries an expectation of improved life expectancy it is also the balance of achieving that whilst maintaining high quality and excellent patient experience.'***

*Anne-Marie Holder (Deputy Medical Director of NHSE Midlands)*

Clive's Review echoed issues raised in the CQC report 'Out of Sight, Who Cares' (2020) [Out of sight – who cares?: Restraint, segregation and seclusion review - Care Quality Commission \(cqc.org.uk\)](https://www.cqc.org.uk/publications-reports/out-of-sight-who-cares) in relation to care provided in specialist hospital settings, and emphasised the critical need for assurance at all levels that people with a learning disability

who are admitted to assessment and treatment units and other specialist hospitals, receive high-quality, specialist care for short periods, which is focused on discharge.

Certainly, there is now greater attention to the oversight of care which is supported by [the Dynamic support register and Care \(Education\) and Treatment Review policy](#). A Community of Practice has been established since December 2022 to support systems with readiness for implementation and post-implementation, with approximately 30 colleagues from across the Midlands systems meeting on regular basis to identify areas of excellence and challenges. There has been increased oversight of people in long term segregation in the form of Independent CETR's recommended by Baroness Hollins' Review and the strengthened roles of host commissioners [NHS England » Learning disability and autism – host commissioner guidance](#) in checking on the quality of providers residing in their localities.

The Safe & Wellbeing Reviews arising from the Norfolk Review [Joanna, Jon and Ben - published September 2021 | Norfolk Safeguarding Adults Board](#) have also provided a comprehensive review of care for people with a learning disability and autistic people currently in specialist hospital settings and local health and care systems are responding directly to the issues identified in safe and well checks. However, it is concerning that many of the issues identified in Clive's review are very much consistent with what the Safe and Wellbeing Reviews evidence as happening today.

The published national report on the findings of the safe and wellbeing checks [NHS England » Safe and wellbeing reviews: thematic review and lessons learned](#) identified that 57% of people who had received a check were in an out of area placement. 41% of people potentially had needs that did not require continued admission to a hospital setting. Many of the issues highlighted in Clive's Review - lack of suitable accommodation, lack of clear formulation or care plan, identified or suspected delays in preparing people for life outside of hospital feature in the reasons why people remain in hospital without a care and treatment need.

The findings also echo the issues of poor patient and family engagement that continue to exist '*There were some examples of effective communication between organisations and family members, but these were far outweighed by examples of poor communication*'. The importance of advocacy was a strong theme in all Safe and Wellbeing regional reports.

The findings raise significant concern around the '*lack of meaningful activities in hospital and the 'boredom' individuals experienced as a result. It was reported that meaningful activities were not consistently available, and where they were, were not always age-appropriate, co-planned and person-centred. There was also a lack of activities to improve people's skills in preparation for their lives and wishes outside hospital, which included but was not limited to, effective access to education and learning, especially for children and young people*'.

A new Mental Health, Learning Disability and Autism Inpatient Quality Transformation Programme was established in 2022 to support cultural change and a new bold, reimagined

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model of care for the future across all NHS-funded mental health, learning disability and autism inpatient settings. Central to this will be the acceleration of new models of care that enable systems to harness the potential of people and communities, within a citizenship model that promotes inclusion and respects their human rights. This programme will complement and further support of existing commitments to improve the quality of community care, and the Mental Health Act reform agenda.

The programme focuses on five themes:

- **Theme 1:** Localising and realigning inpatient services, harnessing the potential of people and communities;
- **Theme 2:** Improving culture and supporting staff;
- **Theme 3:** Supporting systems and providers facing immediate challenges;
- **Theme 4:** Making oversight and support arrangements fit for the sector;
- **Theme 5:** Supporting least Coercive Care (through Reducing Restrictive Practices).

A Commissioning Framework for mental health inpatient services was published in February 2024 which provides more detail [NHS England » Commissioning framework for mental health inpatient services](#)

The National Quality Transformation Programme have also funded NHSE Midlands who have commissioned Midlands and Lancashire Commissioning Support Unit (CSU) to lead a piece of work considering the expansion of the existing Host commissioner guidance that applies to everyone with a learning disability and autistic people, to include people in a mental health inpatient units who do not have these diagnoses.

However, whilst there is greater attention to and provision for oversight of care for people in hospital, access to the voice of patients and their families and carers remains critical to ensure that people are getting the right care and supported effectively out of hospital is seriously lacking. The concern that hospitals are failing to engage people in meaningful activity or prepare them for life outside of hospital is a major concern and one that needs concerted attention. This Conscience Manual will help to keep that focus in sharp relief.

## Epilepsy

***'It should not take the death of a patient to precipitate this kind of collaboration, but I feel (and I hope Elaine feels also) that in Clive's death there has been a real opportunity to shape the way that epilepsy people with a learning disability and autistic people is being delivered and improve choice and quality which has been long overdue.'***

*Ann-Marie Holder, Deputy Medical Director of NHSE Midlands.*



Without a doubt, the actions taken on epilepsy care and treatment will be a lasting positive legacy of Clive's Review. Clive's story has raised the profile of risks associated with epilepsy for people with a learning disability and autism and has been a catalyst for improvement work regionally and nationally.

Informed by the learning from Clive's review, NHSE Midlands Learning Disability & Autism Programme initiated a regional programme of work targeted at reducing premature avoidable deaths related to epilepsy and improving the quality of life for individuals living with epilepsy. The regional programme teamed up with national experts including Cornwall Foundation Trust (FT) (Prof. Rohit Shankar), SUDEP Action, Epilepsy Action and Epilepsy Specialist Nurses Association in the form of a regional Learning Disability and Autism Epilepsy Advisory Group to power this work forward with all 11 Midlands ICS partners. The level of enthusiasm and appetite for this programme of work has been overwhelming and sharing learning opportunities from Clive's review have been oversubscribed and attracted extensive national interest from a wide spectrum of professionals who support people with epilepsy and a learning disability.

Putting in place the foundations needed to achieve better outcomes consistently across the Midlands was a fundamental priority, starting with support for health and care systems to understand their local population and appraise current services, support and pathways. This was a direct recommendation of the Review. All Midlands Integrated Care Systems (ICSs) have been supported to review epilepsy services and support using a tailored Learning Disability and Epilepsy Benchmarking Tool developed by Epilepsy Action. Other areas of work include greater support for individuals and their carers, epilepsy training, the application of assistive technology and capacity and capability in primary care. The outcome of this work is informing the development of local improvements and all systems were asked to report progress in relation this work at local system Learning Disability and Autism Boards.

In response to the challenges and recommendations raised in the report about epilepsy care quality, NHSE (national) also commissioned early on the development of practical guidance for commissioners and care providers (specialist hospital and community) to improve the quality of epilepsy care. This guidance and checklist ([Improving the quality of life and tackling premature mortality for people with a learning disability, autism and epilepsy - NHS Midlands and Lancashire \(midlandsandlancashirecsu.nhs.uk\)](https://www.midlandsandlancashirecsu.nhs.uk)) was successfully launched in November 2023 via a webinar which was attended by over 100 people across health and social care, led by Cornwall FT and SUDEP Action. This will play an instrumental role in improving the quality of epilepsy care and all systems have been asked to implement this into practice.

***“Time and time again over decades the learning from avoidable deaths is the centrality of families being listened to support prevention. This is so clearly true for people with epilepsy and learning disability who have experienced significant and stark public health inequalities over a long time. Working with the Midlands has been a joy.*”**

*Clive and his family have been at the heart of their bespoke independent review and the entirety of the action plan that followed. It has been wonderful to be part of this way of bringing people along the patient safety journey and the openness of all involved has been deeply refreshing. Despite the huge challenges in the system it has been truly inspiring to engage with hundreds of social care and NHS professionals over the year and to witness their dedication to making improvements.*

*The work across the Midlands work is a beacon of hope for the future. We have been thrilled at Sudep Action to have the opportunity to lead on the development of guidance for the commissioning and providing of residential care. We and our expert stakeholders have been pleased to bring together the evidence of what good looks like and engage closely with committed professionals locally on what practical guidance would be useful to them.”*

*Jane Hanna, CEO – SUDEP Action*

In addition, organisations who were directly involved in Clive's care have also taken specific action as noted below:

- **St Andrews** completed their own training needs analysis for epilepsy and are working towards ensuring that 90% of staff have competency-based training for epilepsy.
- **Staffordshire ICB** has worked in partnership with key stakeholders to produce a Joint Strategic Needs Assessment (JSNA). As part of the JSNA Epilepsy Care has been identified as a core priority.
- **Midland Partnership Foundation Trust** has taken forward work to ensure they are providing epilepsy care in line with current NICE best practice guidance. This includes epilepsy care pathway developments, epilepsy training developments and an initial audit to review compliance of practice against the current pathway.

Nationally, the Care Quality Commission (CQC), have engaged with the recommendations of the Review and are working to ensure there are more robust prompts in guidance in relation to epilepsy risk assessment and management plans.

The Independent Chair and the Midlands and Lancashire Commissioning Support Unit consultant were also given the opportunity to submit evidence to the National Institute of Clinical Excellence (NICE) guidelines on epilepsy and this resulted in a greater focus on people with a learning disability and autistic people.

## Health Inequalities

***Clive experienced health inequalities from a young age that had a negative impact on his quality of life, some of which caused him pain and suffering for prolonged periods of time and placed him at risk.***

*Beverley Dawkins (Independent Chair of the Clive Treacey Review)*

The report made a host of recommendations to direct greater attention to issues relating to poor attention to physical health which were brought to the fore in Clive's Review.

Clive's Review, alongside others, has generated much greater attention to physical health needs. For example, in partnership with the Midlands Provider Collaboratives (specialist NHS and independent hospital providers) NHSE Midlands hosted a dedicated event to share and reflect on the learning, which has resulted in physical health becoming a focused priority for the collaborative. The Review has informed and shaped the Midlands Learning Disability and Autism Health Inequalities and Quality Strategy.

Nationally, the CQC are revisiting and reminding all inspectors of the need to review how the physical healthcare needs are being met in services and that all patients have access to primary and specialist healthcare. The rollout of [The Oliver McGowan Mandatory Training on Learning Disability and Autism | Health Education England \(hee.nhs.uk\)](https://www.hee.nhs.uk/learning-disability-and-autism) is underway and will also have a critical role to play in addressing the particular issues of diagnostic overshadowing and reasonable adjustments raised in Clive's Review. It is also particularly pleasing to see the commissioning of a project by the national Learning Disability and Autism programme to develop guidance on sleep apnoea and CPAP machine use for people with a learning disability. This was a very specific issue and risk flagged in Clive's Review.

The Norfolk Safeguarding Review into the deaths of Joanna, Jon and Ben [Joanna, Jon and Ben - published September 2021 | Norfolk Safeguarding Adults Board](https://www.norfolk.gov.uk/learning-disability-and-autism) echoed the findings of Clive's review and in particular issues relating to physical health. The national programme of Safe & Well Checks arising from the Norfolk Review incorporated specific focus on physical health and the published findings of the reviews resonated entirely with Clive's experience.

In September 2023, the Midlands regional Learning Disability and Autism programme worked with Learning Disability and Autism Health inequalities leads to understand the priority areas for reducing health inequalities for people with a learning disability and autistic people. Weight management is an area of focus for many of the Midlands systems in addition to the other areas where there have been avoidable deaths in relation to Cancer, Respiratory and Cardiovascular which is evidenced in the recent 7<sup>th</sup> LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People 2022, <https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-2022-v2.0.pdf>

In November and December 2023 Elaine was a guest speaker at the Regional Health Inequalities Conference and the LeDeR Listening event. Elaine's involvement has been critical to ensure that people continue to hear Clive's voice and to keep systems focussed on how they can keep making a difference to improve the lives of people with a learning disability and autistic people. However, whilst there is greater attention to physical health, systemic visible action targeted at the specific physical health issues in Clive's report, particularly weight gain and meaningful engagement, is still needed.

## Safety and Safeguarding

Clive's review has been instrumental in highlighting the issues of safety and safeguarding that people with a learning disability and autistic people are vulnerable to and the inadequacy of education, health and care systems, at times, to respond to concerns and alerts. The report called for an urgent review by local systems to ensure that adult safeguarding processes in place to protect people with a learning disability are robust and in line with national guidelines.

Clive's review uncovered serious allegations of historic sexual abuse. In response to the review's recommendations, an Independent Safeguarding Review (SAR) was commissioned to evaluate the adequacy of previous investigations and actions taken, as well as to identify opportunities for improvement and learning. Staffordshire County Council is leading this review, and it is anticipated that this will not only provide much-needed answers for Clive's family but also serve as a valuable source of insight on how systems can better safeguard individuals with a learning disability and autistic people to ensure their safety. Staffordshire County Council, as the local authority responsible for Clive's care has also completed a review of the robustness of safeguarding procedures completing 50 case audits for individuals who have been referred in relation to possible safeguarding.

It is also to be noted that Dr Henrietta Hughes, the first patient safety commissioner for England, met with Clive's sister and Beverley Dawkins, the Independent Chair of the Review, within the first 100 days of her appointment. Dr Hughes was impressed by the Review's approach in collaborating with Clive's family to improve quality and safety, and she acknowledged the importance of involving patients and their families in the healthcare process. This meeting is a positive step towards enhancing patient safety and improving the quality of care in England. In addition, both the CQC and RESUS Council welcomed the recommendations in relation emergency response. The CQC committed to revisiting and reminded all inspectors of the need to review that resuscitation training takes place face to face and that resuscitation drills take place in line with national guidance.

The Resus Council has engaged positively and stressed the importance of good person-centred early care planning and risk assessment in line with [ResPECT](#) guidelines/ process [ReSPECT for healthcare professionals | Resuscitation Council UK](#), which 'creates

personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices'. RESUS Council has also produced two videos specifically for people with a learning disability on the ResPECT guidelines.

## Learning from Death Reviews

Clive's Review highlighted that the series of investigations and complaints handling that took place after his death were inadequate and may have resulted in missed opportunities to take action to prevent harm to others. The Review made specific recommendations in relation to strengthening the guidelines for autopsy practice for deaths in patients with epilepsy as well as suggestions for how the newly established Medical Examiner System takes into consideration how death reviews of people with a learning disability and autistic people could be more effective. It has been good to see that the Review has helped key stakeholders to recognise the issues affecting people with a learning disability and autistic people.

Both the Royal College of Pathologists and Midlands Regional Medical Examiner engaged positively and thoughtfully with the findings of the recommendations. The findings of Clive's Review were considered by the Midlands Medical Examiner Forum. A learning disability and autism good practice document has been published ([Good-Practice-Series-Learning-disability-and-autism-For-Publication.pdf \(rcpath.org\)](#)) and shared with all medical examiners and plans are underway for introduction of Continuing Professional Development (CPD) training day to support the implementation of guidance. The Royal College of Pathologists have also considered the findings of the Review and established a working group to review current guidelines on autopsy practice for death in patients with epilepsy.

The 7th LeDER Annual Report [NHS England » Learning from lives and deaths – People with a learning disability and autistic people \(LeDeR\)](#) clearly shows that things are not improving fast enough, and overall care and outcomes all too often still fall below acceptable standards compared to the general population. This is true even with the good and hard work performed by care professionals throughout England, and by improved NHS policy changes. Although there has been a reduction in the proportion of deaths due to avoidable causes, to 42% in 2022 compared to 49% in 2021, this remains much higher than in the general population, and further efforts are required to reduce this. Following a regional LeDeR Listening event held in December 2023, the NHSE Midlands regional team pulled together a high impact actions improvement plan to help guide and steer the system on focus areas for improvement based on a range of views from stakeholders and the evidence-base.

The Midlands LeDeR high impact actions are as follows:

- Reduce avoidable mortality in the 3 clinical priority areas for Learning Disability and Autism (Cardiovascular conditions; Respiratory Conditions; Cancers)

- Focus on co-morbidities associated with premature death
- Assure and Sustain Performance of LeDeR review completion within 6-month KPI (Understanding, addressing and monitoring variation in performance across the region)
- Improve the quality of LeDeR reviews and actions from learning and facilitate peer review opportunities
- Improve access and understanding of importance of LeDeR reviews, including communicating more with stakeholders encouraging referrals to LeDeR to better understand the experience of LeDeR for families and relevant others particularly minority ethnic groups and autistic people
- Improve accuracy of Learning Disability Registers & Increase the quality and uptake of Annual Health Checks (AHC) and support continued improvements in data accuracy for thematic analysis

## Clive's Challenge

***'One of the most striking things about Clive's story is the shocking lack of ambition that professionals and services had for him. Even at the age of 16, his college tutor notes that 'his hopes for the future are unrealistic'.***

*Beverley Dawkins, Chair of the Clive Treacey Independent Review*

Clive's hopes for his future were ones repeated often to his family and to anyone else who would listen. Clive wanted to have his own home, a ground floor flat or a bungalow near his family, a cat, and a garden, to go on holiday to Blackpool, to go on holiday to Bream in Somerset where he had spent many childhood holidays, to be able to do his photography, art and gardening and to work in a garden centre helping to grow plants. This is what many staff said they had found most powerful in reading Clive's Report:

***'Continually challenge views, decisions and inaction. I want to treat each person as if they were my own family member'***

***'Keeping this feeling fresh is crucial so we need continual challenge'.***

***'To remain connected with why I do this role to make a positive difference. Getting culture and work practices right to ensure quality of care is excellent. To challenge when it is not there'***

## Do it Clive's Way!

Clive's review captured the journey his life took and how he remained very far away from that dream. This is an all-too-common story for people with a learning disability and autistic people so this conscience manual ends by challenging professionals, practitioners and commissioners to think and act in ways that bring people closer to finding that place to call home. This is what **you** can do:



**See the person, hear the family, recognise the ambition!**

## Glossary

Term	Description
ADASS	Association of Directors of Adult Social Care: promotes higher standards of social care services and influence policies and decision-makers to transform the lives of people needing and providing care
Annual Health Check (AHC)	The learning disability annual health check is a reasonable adjustment that can be effective in detecting unmet health needs.
Care, Education and Treatment Review (C(E)TR)	A C(E)TR is a person-centred review to ensure the care (education) and treatment and support needs of the individual person and their family are met, and that barriers to progress and/or discharge are challenged and overcome
Community of Practice (CoP)	A learning network of people who share a skill and who improve as they interact and learn from each other on a regular basis
Continuing Professional Development (CPD)	Formal and informal learning experiences which help clinicians and practitioners develop and improve their professional practice
Foundation Trust (FT)	An NHS organisation which gives greater opportunities for people, patients and staff who have a genuine interest in the Trust to have more of a say about the way in which services are provided.
CPAP machine	A continuous positive airway pressure (CPAP) machine is the most commonly prescribed device for treating sleep apnoea disorders
Commissioning Support Unit (CSU)	Commissioning Support Units (CSU) provide Integrated Care Boards with external support,



	specialist skills and knowledge to support them in their role as commissioners.
Care Quality Commission (CQC)	CQC is the independent regulator of health and adult social care in England.
Diagnostic Overshadowing	Diagnostic overshadowing occurs when a health professional makes the assumption that the behaviour of a person with a learning disability is part of their disability without exploring other factors such as biological determinants
Epilepsy Action	Epilepsy Action is a charity that is working to improve the lives of everyone affected by epilepsy
Integrated Care Systems (ICSs)	Partnerships that bring together NHS organisations, local authorities and others to take collective responsibility for planning services, improving health and reducing inequalities across geographical areas.
Learning Disability and Autism Partnership Board	Learning Disability and Autism Partnership Boards bring together lots of people in local areas to work on making things better for people with a learning disability, autistic people and their families.
LeDeR	National programme to develop learning from lives and deaths of people with a learning disability and autistic people (LeDeR)
Local Authority	A UK Local Authority (often called a local council) is an elected body that provides a range of services for a particular geographical area in the United Kingdom.
Mental health inpatient units	Mental health inpatient services are for people who can no longer be supported at home and need to be admitted to a specialist hospital due to severe mental health problems

National Institute for Clinical Excellence (NICE)	Provides guidance, advice, quality standards and information services for health, public health and social care.
NHS England Midlands	NHS England – Midlands is one of seven regional teams that support the commissioning of high quality services and directly commission primary care, public health and specialised services.
RESUS Council	Resuscitation Council UK is an organisation dedicated to saving lives by developing guidelines, influencing policy, delivering courses and supporting cutting-edge research.
Sleep apnoea disorder	A relatively common condition where the walls of the throat relax and narrow during sleep, interrupting normal breathing.
Special educational needs and disability (SEND)	A child or young person has special educational needs and disabilities if they have a learning difficulty and/or a disability that means they need special health and education support
SUDEP Action	SUDEP Action is a charity dedicated to raising awareness of epilepsy risks and tackling epilepsy deaths including Sudden Unexpected Death in Epilepsy.

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