

## Oxfordshire Clinical Commissioning Group Board Meeting

<b>Date of Meeting:</b> 27 July 2017	<b>Paper No:</b> 17/50
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**Title of Paper:**

Review of deaths of people with a learning disability people within Oxfordshire's commissioning responsibility who died between 1 April 2011 and 31 March 2015.

<b>Paper is for:</b> (please delete tick as appropriate)	<b>Discussion</b>	<input checked="" type="checkbox"/>	<b>Decision</b>	<input type="checkbox"/>	<b>Information</b>	<input checked="" type="checkbox"/>
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**Purpose and Executive Summary:**

This paper is in place of the Safeguarding paper.

*The Independent review of people with a learning disability or mental health problem in contact with Southern Health NHS Foundation Trust April 2011 to March ('Mazars')* recommended a retrospective review of all learning disability unexpected deaths with particular reference to 10 areas which were identified by Mazars as particularly significant for people with learning disabilities.

Oxfordshire CCG began this review immediately after Mazars was published. The review was not confined to unexpected deaths. It looked at the death of every Oxfordshire patient with a learning disability who died between 1 April 2011 and 31 March 2015.

The CCG undertook a two stage review. This paper sets out the findings of this retrospective review.

**Financial Implications of Paper:**

None

**Action Required:**

For the Board to note the contents of the report

**OCCG Priorities Supported** (please delete tick as appropriate)

<input checked="" type="checkbox"/>	Operational Delivery
<input checked="" type="checkbox"/>	Transforming Health and Care

	Devolution and Integration
✓	Empowering Patients
✓	Engaging Communities
	System Leadership

**Equality Analysis Outcome:**

People with learning disabilities die younger than the population as a whole. This paper examines out the causes of death of people with learning disabilities.

**Link to Risk:**

This work is linked to the risk around quality of care for people with a learning disability.

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# **Review of deaths of people with a learning disability people within Oxfordshire's commissioning responsibility who died between 1 April 2011 and 31 March 2015**

## **1. Background**

The *Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015* was commissioned by NHS in July 2013. This report is commonly referred to as 'Mazars'.

The report looked at all deaths of people in receipt of mental health and learning disability services in Southern Health NHS Foundation Trust between April 2011 and March 2015. The report reviewed the reporting and investigation of unexpected deaths for people with learning disabilities and or mental health problems. It found wide variation. In learning disability the rate of investigation was particularly low. The report also found that the engagement with families in the event of unexpected deaths was poor.

This under-investigation of deaths meant that opportunities to learn had been missed. The report set out ways in which this inequality should be addressed.

One of the recommendations of the report was that a retrospective review be undertaken of all mental health and learning disability deaths of people in receipt of care from Southern Health during this period should be investigated.

## **1. Introduction**

This report is part of Oxfordshire CCG's response to Mazars. This report looks at the deaths of all people within Oxfordshire's commissioning responsibility<sup>1</sup> with a learning disability who died between 1 April 2011 and 31 March 2015.

It is important to note that in Oxfordshire, for the first 19 months of this period, learning disability services were provided by the Ridgeway Partnership NHS Trust a stand-alone learning disability trust. The Ridgeway Partnership trust was taken over by Southern Health on 1 November 2012. This period of 19 months between 1 April 2011 and 31 October 2012, was not included in the Mazars report as it was looking solely at Southern Health NHSFT. However, when undertaking the retrospective review Oxfordshire Clinical Commissioning Group (OCCG) took the decision that this 19 month period should be included.

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<sup>1</sup> There are complex rules around 'responsible commissioner'. Some of the people we reviewed were Oxfordshire patients who had not lived in Oxfordshire for decades.

It should also be noted that because mental health services in Oxfordshire were not provided by Southern Health this report will only review learning disability (LD) services, and not Mental Health services which are provided in Oxfordshire by Oxford Health NHSFT. Oxfordshire CCG is working with providers of mental health care in Oxfordshire to ensure that they take forward the recommendations of Mazars. For the purposes of this review and this report we are looking at the care and treatment of people who were registered with Oxfordshire County Council as having a learning disability.

## **2.1 Mazars Requirements for CCGs**

The Mazars report recommended that 'the Trust, CCG and local authority undertake a retrospective review of all learning disability unexpected deaths regardless of place of residence with particular reference to:

- The quality, timing and follow up of dysphagia assessments
- The level of support provided by hospital liaison services and the challenges faced in acute liaison
- The decision-making process for PEG insertion
- The hydration and nourishment of service users refusing to eat
- Delays in decision-making for treatment - including primary care, decisions by care staff and responses in A&E and on wards
- The inclusion of carers and families in investigations
- Waiting times for therapy services and community nursing
- Identification of early warning signs of deterioration through behavioural change
- Arrangements for attending appointments and seeing healthcare professionals
- Reporting and acting on safeguarding concerns.'

This OCCG review includes, but is not limited to, the areas identified in the Mazars report.

The OCCG review found some of the areas identified by Mazars to be significant in Oxford while others were not. . The OCCG review also found some areas not singled out by Mazars which were considered to be significant in Oxfordshire. Healthcare for people with learning disabilities is not provided by a single trust. While Southern Health, and before them The Ridgeway Partnership Trust provided learning disability input for the majority of the patients we reviewed, these patients will all have been treated in primary care, and many of them will have been treated in community care and acute trusts. These providers were outside the scope of Mazars but their input is vital to understanding the health and outcomes of people with learning disabilities.

Mazars focused on an NHS provider which also provided some social care. The importance of social care provision should not be under-estimated. The majority of day to day care for people with learning disabilities is provided by social care providers rather than health care providers. Some, but not all social care was provided by the Ridgeway Partnership Trust (which was a combined health and social care learning disability trust) and by the social care arm of Southern Health NHS Foundation Trust, called TQ21.

The OCCG retrospective review seeks to reflect this complexity by including all these organisations in the review process.

### **LD and Mortality**

It is established that people with LD die younger than the population as a whole. Pauline Heslop's team at the University of Bristol has shown there is approximately a 16-20 year disparity between age of death for people with learning disabilities and the population as a whole.

There has been an increasing median age at death over time (from 53 to 57 years from 2008-2011) but there is 'little evidence of any closing of the gap in age-standardised mortality rates or life expectancy between people with learning disabilities and the general population' (Emerson et al. 2014 p.94).

It is important to note the distinction between preventable mortality and amenable mortality. Preventable mortality refers to all or most deaths from a cause which could be avoided by public health interventions in the broadest sense. Amenable mortality refers to all or most deaths from a cause which could be avoided through good quality healthcare. Preventable mortality is the same in the learning disability population as in the general population at 21%.

For amenable mortality however, the rate in the learning disability in the general population is 13% whereas in the LD population is 36.5%.

This means that almost three times as many people with LD die of causes which could be avoided through good quality healthcare as do the population as a whole.

There is consistent evidence from research that the learning disabled population have greater healthcare needs than the general population. This includes:

- Gastrointestinal cancer is proportionally higher.
- Children with Down's syndrome are at higher risk of leukaemia;
- Coronary heart disease is a leading cause of death in this group;
- Respiratory disease is much higher than the general population;

- Increased incidence of psychiatric disorders, schizophrenia and challenging behaviours.
- The risk of dementia is greater (and occurring at younger stages of life);
- Epilepsy has been reported as 20 times higher than in the general population;
- Increased incidence of sensory impairments (e.g. hearing or vision);<sup>2</sup>

## **2. OCCG review, design and process**

No guidance was given as to how the retrospective review of deaths should be undertaken. OCCG therefore developed a two stage process. Legal advice was sought to support our approach. The terms of reference for the review are attached as appendix 1.

The aims of this process were:

- To gain a better understanding of the causes of mortality and morbidity of people with learning disabilities in Oxfordshire.
- To ensure that past deaths had been sufficiently investigated and that duty of candour had been fulfilled.
- To understand whether and how this ill health may be amenable to care
- To take action to improve future care

The review was designed as a two stage process. We sought the input of Oxfordshire Family Support Network (OXFSN) on the design of the review. We also asked OXFSN to raise awareness of the review in the community. Following the publication of Mazars a helpline was established for people who felt the issues exposed had implications for them. A small number of calls were made in Oxfordshire.

## **3. Stage one review**

In stage one of the investigation all patients with a learning disability known to services who died between the dates of 1 April 2011 and 31 March 2015 were identified. This was a larger number than the number considered by Mazars because it also included

- Patients under the care of Ridgeway for the period 1 April 2011 to 31 Oct 2012. This was prior to Southern Health NHS FT taking over the Ridgeway trust on 1 November 2012.
- Oxfordshire patients in receipt of services who may not have been known to Southern Health

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<sup>2</sup> Consistent evidence from PHE Improving Health and Lives Learning Disabilities Observatory.

There were a number of possible sources of the list of people. It was not possible to access the list used in the Mazars review. OCCG therefore accessed and reconciled all the information available. At all stages the approach has erred on the side of including a person in the review when there was doubt, with the intention of minimising the risk of somebody being missed.

Mazars identified 57 Oxfordshire patients with a learning disability known to Southern Heath who died between 1 November 2012 to 31 March 2015. The total number of people with a learning disability who were on the Oxfordshire County Council's register who died between 1 April 2011 and 31 March 2015 was 106.

The CCG uses the risk management software Datix to manage complaints, incidents and feedback. Datix was used to compile a database of the 106 patients. The database was designed to bring together a range of information about the person. In addition to demographics, place and type of residence and place of death were included. Safeguarding alerts information held by OCC was added to the database. Details of next of kin and the family involvement were also included. As the investigation progressed additional information collected was included in the database to keep track of activity for each case.

#### **4.1 Cause of death**

A clear cause of death was essential for this review. The only place this could be reliably accessed was from the death certificate held by the registrar. For deaths outside of Oxfordshire the death certificate was sought from the appropriate registrar. The registered cause of death from the death certificates was added to the record.

For each patient, a view was taken as to whether there was sufficient information to decide whether or not the case required further investigation. In some cases it was sufficient to provide assurance that there was no need for further information in order to be satisfied that the person had received appropriate care.

This decision was made by the named GP along with a senior manager with experience of quality issues in services for patients with learning disabilities. If there was any doubt the patient was included for further investigation rather than excluded. There was no rigid cut-off age for investigation, meaning that the death of patients in their 70s would still be investigated if the review team felt there maybe something to learn from their care. There were 17 patients who were 61 or older, two of whom were over 71.

Of those going through to the stage 2 review 24 died in hospital. Overall the top cause of death was Pneumonia. For those going through to stage 2, there were seven deaths from

aspiration pneumonia and nine deaths from broncho-pneumonia. Four had epilepsy listed as cause of death.

## **4.2 The categories of expected and unexpected death**

For the purposes of this review, the use of the term 'expected' or 'unexpected' to categorise deaths was not helpful. While this terminology is widely used it was felt that it may limit the review. For example, a death from cancer may make the death 'expected' but it may also have been amenable to better healthcare, if, for example, the cancer was detected late.

## **4.3 Duty of Candour/involvement of families and user led organisations**

Throughout our review OCCG sought to keep the families and carers of the people who had died informed of the process. We sought advice from the Oxfordshire Family Support Network (OXFSN) on the design and the approach of the review. As set out above, we publicised the review from the start.

Once the first stage of the review was complete we wrote to all next of kin for whom we had details.

Finding next of kin details for those who had died was very challenging. We requested this information from providers, who we hoped would have the data recorded on their systems. Many of the service users had no next of kin recorded. The project manager followed up contacts for each person on the list to try to establish their next of kin. We managed to find details for 63 of the 100 cases. All of these were written to, setting out the review process being undertaken. We advised the next of kin whether their family member's case would be being further investigated. For both groups we asked how they would like to be involved in the review process going forward. We gave the next of kin the opportunity to challenge our decision not to investigate further.

For those who were going to be further investigated we asked them to provide a 'pen portrait' to be included in the review material.<sup>3</sup>

There was a wide range of responses to the letter. A large number did not reply. Some got in touch to say they did not wish to be involved further. Several families provided us with additional information. In a small number of cases this related to historic complaints.

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<sup>3</sup> Pen portraits are a device for giving a sense of the person, and in doing so putting the person at the centre of the investigation. The portrait is written by someone who knew the person well, and describes their personality, likes and dislikes. I



## **5 Stage two**

Recognising that there was no established method for conducting this type of review, and understanding that one of the central purposes of the investigation was to improve the care of people with LD across the system, we opted to conduct a multi-disciplinary review of the 40 cases we had identified as requiring further investigation. We used a model which had been used in child safeguarding to review multiple cases. We wanted to achieve a multidisciplinary review for each of the cases. The idea was to bring together representatives from across agencies to review each of the remaining 40 cases. Further, we wanted any parallels between the cases to be drawn.

The review was conducted under the governance structures of the Oxfordshire Adult Safeguarding board to enable data sharing.

### **5.1 Method**

For each case, completion of an audit template was requested from all the agencies involved. The template collected some general details about the person, and also asked some specific questions around the areas identified in Mazars.

For each person we also tried to get a 'pen picture' to give the reviewer a sense of the life they were looking at. Some of these pen pictures were provided by next of kin, others were provided by staff. Other contributions from families and carers were also added to the information we collected via the audit.

The audits and pen pictures were put together to form case files.

We invited representatives from all agencies who are involved in the care of people with learning disabilities in Oxfordshire.

#### **5.1.1 Primary Care Records**

It is important to note that the review was significantly hindered by primary care records being inaccessible. This is because the contract for storing records had recently been changed. The archived records had been moved without a workable labelling system. As a result, GP records for deceased patients were inaccessible for some months. At the time of writing a small number of records have been made available. These have been reviewed in conjunction with the other information collected.

For a number of cases the GP was identified through the others agencies' review and the practice was contacted directly. In this way we were able to add GP electronic data

summaries to our information. This went a small way to filling the gap, but the lack of primary care information was a significant gap in the review and this hampered the review process on the two days.

### **5.3 The Event**

As a result of the findings of stage one, the cases were split into two groups: those with respiratory causes of death and those with other causes. Around half the cases for stage 2 had a respiratory cause of death. For this reason it presented a logical split in how to use the days.

Two events were held two weeks apart in November 2016. Each of the events looked at 20 cases. Case files were prepared, combining the audit sheets with the pen portraits, demographics, safeguarding information along with any other information which had been provided.

The events were multiagency, with representation from:

- Oxford University NHS Hospitals NHS FT
- Oxford Health NHS FT
- OCCG
- OCC
- Oxfordshire Adult Safeguarding Board
- Southern Health NHS FT
- Social care providers
- Oxford Family Support Network (OXFSN)
- Thames Valley Police
- Improving Health and lives (Public Health England).
- GPs
- NHS England

While we had representation from all the agencies involved in the care of the individuals, it was only sometimes possible to have somebody present who knew the individual. Where possible we facilitated this contribution by moving delegates around.

The delegates were split between ten tables, ensuring a mixture of agencies at each. Each table had a facilitator and was asked to review two cases. Each table was given the morning to review two cases. They were asked to review the file, provide an overview and to identify

whether there had been gaps in care. Each table fed back on themes, surprising issues and notable practice. The afternoon was spent reviewing the themes which emerged from the morning.

We revised the format of the day slightly to reflect feedback from day one. The second day looked at all the other causes of death.

## **6. Reflections on past practice**

A clear message of the days was the extent to which clinicians felt that the care which is being provided is different from the care which had been provided in the past. The cases we looked at were of people who died between 2011 and 2015 and reviewers were looking at a lifetime of care and issues. As a result, much of the care which was being reviewed was many years ago. We know that early decisions about care have long-lasting effects on health outcomes. Medicine has also advanced in this time and attitudes toward disability have changed.

Since the event, clinicians have written to provide examples of how care has changed since this time. It cannot be claimed that there has been complete change, but there has been development of practice. This is due, at least in part, to increased awareness of the issue of learning disability.

In order to identify aspects of care that need to be considered moving forward the report has identified themes.

### **6.1. Care coordination and care planning**

The lack of care coordination was identified as an issue in multiple cases. As the reviewers of each case were looking at audits from many agencies the difficulties with care coordination became very apparent.

For people with active family carers, these carers often took the role of care coordinator. It was these family carers who ensured the links were made between agencies and who followed up on recommended actions. Where there was no family coordinator/advocate, things were much more difficult. No one single person or agency took the role of overseeing the care for an individual. For this reason the pieces often weren't 'put together' and the appropriate action sought. From the position of hindsight the reviewers could see where actions had been omitted, or when things had not been followed up. There was no evidence that people with learning disabilities were more likely to experience errors and omissions. It

was clear however, that when they did they were less likely to be picked up. So for example, one person was told at a hospital visit to go back to their GP to request a changed prescription. This GP visit did not happen and the patient's medication was not changed.

Most cases we looked at had a large number of inputs from a wide range of agencies, providing many opportunities for things to be missed.

The number of different services, professions and approaches in the room was remarkable. While this is undoubtedly positive, it makes knowledge and understanding a challenge. In a room with 50 highly experienced practitioners from across health and social care a large number commented on gaps in their knowledge as to the roles of other professionals and agencies. The range, organisation and provision of services is complex and changes frequently. If awareness of the range of services is challenging for professionals, it is not surprising that it can be extremely challenging for people with learning disabilities and their families.

There was a view that a clear record of what services were out there and how they linked would be of benefit.

Linked to the idea of the care coordinator was the recognition of the need for holistic assessment and care planning. In a number of cases the reviewers felt that no one 'held a complete picture' and that had they done so, care could have been provided more effectively. This was more pronounced when a close family member was absent. It was also recognised that the care coordinator needed to have access to highly skilled professionals for advice and support. The production of a care plan in an accessible form is important not just for the person with learning disabilities, but also for the staff who support them. A single multiagency accessible plan with a key named person in a coordinator role is essential.

## **6.2 Working with families**

Mazars identified poor working with families in the event of a death. The OCCG review went wider than this and asked the reviewers to consider how services had worked with families in general.

There were some very good examples of working with families. Many of the responses from the next of kin reported very positive experience of care. The best examples were where the family were treated as a part of the team around the individual and were viewed as partners in care.

However, there was also a theme of families being seen as a problem. Families described having to 'fight' for the right care for their loved one. In two cases a past breakdown in care meant that families resisted subsequent moves, which were for sound care and support reasons, for fear that they would lose the quality of care they had fought for. Families who complain can be perceived by services as difficult when in fact there are trying to support their relative's best interest. Families also reported being fearful of complaining for fear they would be labelled as difficult and that their relationship with services would suffer further as a result. In some cases there appeared to be conflict between the family's wishes and preferences for the individual and the view of professionals and staff as to what would be best.

There was a theme apparent of staff seeing themselves as 'on the side of the patient'. In particular, when the person with a learning disability becomes an adult, families reported that they felt 'shut out' of care. On occasion this amounted to the supposition of a conflict between the family and the young person where none existed. It is important that adults with LD are supported and empowered to make their own decisions. This should not mean that families are not a part of these decisions.

It was recognised that training on both sides was beneficial. Training in empathy for the staff and training in speaking up for the families. The OXFSN 'Embolden' project was noted as a good example of training for families. Improved training in the appropriate application of the Mental Capacity Act and best interest decision making would also be beneficial in resolving some of the conflicts.

### **6.3 Late, or lack of, detection of deterioration in health**

In many cases, the retrospective review enabled the reviewers to see where health conditions had developed or worsened. With the benefit of hindsight, earlier signs of the health deterioration could be seen. This is likely to be the case to a certain extent for the population as a whole. Once a diagnosis has been made, previous symptoms become explicable in the light of this diagnosis. We know, however, that many more people with learning disabilities die of conditions which are amenable to appropriate health intervention than do the general population. We also know that people with a learning disability are likely to have health conditions diagnosed later, sometimes as a result of 'diagnostic overshadowing.'<sup>4</sup>

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<sup>4</sup> Diagnostic overshadowing refers to the negative bias impacting a clinician's judgment regarding co-occurring disorders in individuals who have intellectual disabilities or other mental illness. Symptoms

One of the themes detected at the review events were the skills of support workers to spot and respond appropriately to health issues. When the health need has been detected they then need to ensure actions are followed through. In more than one case, assistive technology was in place but it was felt that carers were not using it, or not using it appropriately.

It is essential that care plans are comprehensive, up to date and accessible. This is essential both for the person with a learning disability and for the support workers.

It was recognised that general increase in health literacy would be beneficial to this.

The development of skills and training for support workers is essential. The recruitment and retention of support workers with the skills we would want is extremely challenging, particularly given the terms and conditions.

#### **6.4 Issues with patients placed out of area.**

It is well established that for a wide number of reasons, it is almost always preferable for people to be placed locally. Situations where patients are placed out of county, where patients from out of county are placed in Oxfordshire and where patients have packages of care funded by more than one commissioner present a challenge in terms of care coordination, holistic assessment and care planning.

There were some indications from the review that that people who are placed out of county may receive care of a lesser quality. Comprehensive and regular reviews are an important part of case coordination and people placed out of area appeared to receive less frequent reviews. For example, if a patient is placed out of area where patients are registered with a local GP for their primary care and are neither eligible for section 117 nor continuing health care. In this case, Oxfordshire CCG has no responsibilities for the quality of healthcare and OCC's responsibility for assurance of quality is unclear.

It appeared that people who were placed out of area were reviewed less frequently. This was particularly the case where people were in settled accommodation and where they were using local services.

It is difficult to draw clear conclusions in this area and the information we had for people placed out of area was less robust. While it is certainly true that out of area information is

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or behaviours that may be due to a specific mental illness are attributed to another disorder, historically learning disability, without considering alternative aetiology.

more complex to access, the project manager spent a lot of time tracking down details for patients who were 'out of area'. This led us to surmise that there are fewer records, containing less information which is less frequently reviewed for people who are placed out of area.

The solution to this is clear: people should only be placed out of area in exceptional circumstances. It is acknowledged that people placed out of area in the past may not wish to return to Oxfordshire. When someone is placed out of area, there should be robust mechanisms in place to ensure they are reviewed at least as frequently as in area patients. Where being an out of area patient presents particular challenges this needs to be clearly and explicitly addressed and the risks clearly managed.

### **6.5 Decision making, capacity and advocacy**

The pre-event audit requested information about the application of the Mental Capacity Act (MCA).

We found assessments of mental capacity to be lower than we would expect. We also found that there were some cases where people had a do not attempt cardiopulmonary resuscitation (DNACPR) in place but there was no clear documentation of the decision making behind this. Part of this will be down to the fact that we were looking at historic cases. The correct application of the Mental Capacity Act is a legal requirement. However, the routine use of the act requires a cultural shift. This change will take some time. Providers must work to ensure all their staff are aware of the requirements of the MCA.

The value of advocacy was recognised by all. It was agreed that advocacy needs to be promoted and used more widely. In particular the value of advocacy was highlighted where there is disagreement or conflict.

Services need to work with advocacy services wherever possible to work to maximise the ability of the individual to communicate and to make decisions about their life.

### **6.6 Management of epilepsy, use of assistive technology and training of people to use technology.**

Epilepsy was a cause of death in six of the cases subject to multidisciplinary review. Many of the people with a different cause of death also had epilepsy and the management of the condition had a significant impact on their health and quality of life.

The issues which were discussed around epilepsy link to several of the other themes. A level of skill is required to support someone with epilepsy. The ability of the social care staff to care for the person with epilepsy are essential for this group of people.

Again, much of this comes down to care planning. Good care oversight and coordination are essential to ensure that the right skills are in place to support a person with epilepsy.

The potential for assistive technology to support the needs of a person with LD and epilepsy was also highlighted. Used well, assistive technology has the potential to support a person to have more choice and control over their life and have fewer restrictions. If this is to work it is essential that the individual and the care staff who support them are adequately trained in the use of the technology and are able to respond when the technology alerts them.

## **6.7 Commissioning**

One of the clearest themes was the sense that the social care being provided did not meet the needs of the individual. More than one family reported feeling as if they were 'forced into accepting a placement which they did not feel to be the right one. Similarly, the providers reported that they felt that sometimes the needs of individuals were greater than they had been led to believe at placement.

Individual needs do not stay the same and changes, usually increases in need, presented a particular challenge to providers.

Providers need an ability to flex provision according to individual needs. This flexibility is also required in universal services, which should make reasonable adjustments in order to support people with learning disabilities such that they receive equality of outcome.

Quality checking of provision is essential. It was apparent from the cases which were reviewed that in the past the quality of social care placements was below the standard we would expect today. The use of 'experts by experience' adds a valuable dimension to quality checking. The reviewers, which included social care providers, also suggested increased use of peer review between providers to support high quality and share learning.

## **6.8 Workforce**

The needs of people with learning disability will vary depending on the impact of the disability on their ability to lead a full and meaningful life. The workforce required to support people must reflect this diversity of needs. Historically the learning disability workforce has not received much attention. With the Transforming Care agenda there is greater recognition



that people with learning disability need to be supported by staff with the right skills to meet their needs.

People with learning disabilities, living with their families or in supported living, need to have good access to GP services, including annual health checks and screening services. The workforce needs to be highly skilled in communication, recognising that some people may be nonverbal or have other auditory and visual challenges. It is an essential skill when working with people to understand their mental capacity, and to work with the individual and within the law to maximise the choice and control they have over their life. A clear knowledge of the tenets of the Mental Capacity Act and when and how additional expertise should be sought is essential.

Certain conditions such as epilepsy are more prevalent in people with learning disabilities. One in three people with learning disabilities also have epilepsy. It is essential therefore that the workforce have skills in managing epilepsy and understanding the pathway of care for the individual.

Mental health problems also have a higher prevalence in the learning disability community. It is essential that mental health issues are differentiated from behavioural issues which may require different interventions to support the individual.

It is essential that workforce development is undertaken to support the future of service for people with learning disabilities.

## **7. Follow up of cases after the events**

During the two one-day events a number of cases were highlighted which the reviewers felt required a further level of scrutiny. In total there were 13 of the 40 cases which required further action.

Following the event the cases were again reviewed by a small team to establish whether further action on individual cases was indicated. Further information has been sought for all of these cases. This has included accessing the primary care records, which, as set out above, were not available at the time of the review. One case was referred in full to the SAR in full subgroup of the adult safeguarding board and is currently being considered as to whether it requires a safeguarding adult review.

All these cases have now been reviewed

## **8. Conclusions**

### **Transforming Care Programme (TCP)**

Learning disability care is subject to the national Transforming Care programme. In Oxfordshire transformation is taking place alongside a change in provider of learning disability health care services.

There is now a national requirement to review the deaths of all people with a learning disability. Oxfordshire has established a 'Vulnerable Adults Mortality Subgroup of the Oxfordshire Adult Safeguarding Board. This subgroup will follow LeDer (learning disabilities mortality review programme) methodology to ensure that all deaths are reviewed.

### **Learning points**

1. Excellent care coordination is essential and is a central part of care planning.
2. Services should work in partnership with families and carers.
3. Annual health checks have been established as good practice for a number of years. However, in Oxfordshire, the number of people with learning disabilities receiving an annual health check is low. A regular comprehensive health check would help to detect health issues early. Work on full implementation of health checks is ongoing through the Transforming Care Programme.
4. High skilled workforce is essential for learning disabilities care. The development of a workforce plan is a key part of the TCP
5. Knowledge and correct application of the Mental Capacity Act should be promoted. All employers should ensure that their staff are competent in this area. In particular, providers should ensure their support staff have a good level of health literacy
6. There needs to be a robust quality assurance process to ensure that providers are delivering care to a high standard. Where quality falls below the expected standard there needs to be a clear process for addressing this.
7. Mainstream services should make reasonable adjustments to ensure equality of outcome.
8. The quality of care provided to people who are placed out of Oxfordshire should be equal to that provided in county. An enhanced level of scrutiny of out of area placements is necessary.

## **Appendix 1**

### **Findings in relation to the Mazars categories**

The two Oxfordshire learning events did not follow the categories set out by Mazars. The areas of focus were instead developed from looking at the cases and identifying themes.

The Oxfordshire cases have been considered in relation to the Mazars finding and the findings are set out below.

#### **A) The quality, timing and follow up of dysphagia assessments**

We did not find that referrals for dysphagia assessments were delayed. We did, however, find that a high number of people with learning disabilities had gastric and/or respiratory causes of death. It is not clear at this stage how much of this morbidity would be amenable to better quality healthcare. Further research is required in this area.

**B) The level of support provided by hospital liaison services and the challenges faced in acute liaison**

Acute liaison was not identified as a lack in Oxfordshire. In fact the liaison service at the Oxford University Hospitals trust is consistently identified as excellent by services users, their families and carers.

**c) The decision-making process for PEG insertion**

It was not clear from the evidence that there were adverse decisions in this respect.

**d) The hydration and nourishment of service users refusing to eat**

Again, while not an uncommon issue we did not find that this was a problematic area in Oxfordshire. We did find that nutrition in social care settings was an area identified for improvement particularly where people had a high level of independence.

It was agreed that it is important to balance quality of life, individual choice and managing risk when it comes to supporting individuals with nutrition.

**e) Delays in decision-making for treatment - including primary care, decisions by care staff and responses in A&E and on wards.**

None found

**f) The inclusion of carers and families in investigations**

The cases which we looked into were those which had not previously been investigated. This meant that the deaths had not, for the most part, been identified as 'incidents' and there was no investigation with which the families could become involved.

What we did find was a number of families who had unresolved issues. There may have been historic complaints, or families who did not find that the complaints were investigated to their satisfaction. Families often report a 'battle' with services. In more than one case an historic experience of a person with and LD being in a poor social care setting meant that the family became very wary about any changes to provision in the future. This was a particular

challenge when there need to be changes as families are scared of losing what has been so hard fought for.

**g) Waiting times for therapy services and community nursing.**

Waiting times were not identified as a significant issue by our multi-disciplinary process. However, there was a suggestion that people were not being referred to services when they should have been. This could be as a result of a lack of understanding that a specialist opinion was required, or it could be due to a perceived lack of availability of services.

**h) Identification of early warning signs of deterioration through behavioural change**

The late identification of health need was clearly identified and is discussed above. This included health need which could have been identified through behavioural change and health needs apparent from other symptoms.

**i) Arrangements for attending appointments and seeing healthcare professionals**

We did not find evidence that appointments were missed. However, we did find evidence that people did not have the right level of skill to support them at appointments. We also found that this sometimes resulted in actions not being followed up on in a timely way.

**j) Reporting and acting on safeguarding concerns**

There was a lot of evidence of safeguarding concerns being raised and responded to. Safeguarding information was a useful source of information on problems which had been encountered with care. We did not find evidence that concerns raised were not acted upon.