



LOCAL SAFEGUARDING ADULTS BOARD MULTI-AGENCY REVIEW

Adult H

Final Report – November 2017

Author: Eliot Smith, Named Professional for Safeguarding Adults
Southern Health NHS Foundation Trust

Theresa Gallard, Quality Manager
Southampton City CCG

PREFACE

In 2016, the Southampton Local Safeguarding Adults Board (LSAB) considered the case of Adult H, a man with a diagnosis of severe learning disability and autism who sadly died following a short battle with cancer.

The LSAB considered the case carefully and concluded that did not meet the statutory criteria for a Safeguarding Adult Review. The Board agreed however, that there was significant learning that could be drawn from this case and so a Multi-Agency Review was commissioned. The focus of the review is to move beyond the specifics of this individual case and to identify the underlying issues that are influencing practice and contribute to improving practice within a whole systems approach.

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INTRODUCTION

Adult H had a severe learning disability, and needed support in all activities of daily living, requiring support from two carers. He had little insight into his health needs and had severely limited communication skills. Adult H was unable to understand complex information even using adapted information. Adult H was able to understand some very basic information in the context of his familiar routines. He relied on people who knew him well to be able to understand him, and respond to his needs appropriately.

Adult H was unable to communicate pain effectively, and demonstrated this through behaviour. On 3rd January 2016, Adult H sadly died following a short battle with Oesophageal cancer. Concerns were raised about the way in which agencies worked together to respond to the physical health needs of Adult H. In particular it was believed that there were a number of potential points in the provision of healthcare services where Adult H's cancer diagnosis may have been confirmed earlier, enabling an opportunity for an improved palliative care response, or lifespan/quality of life. This case highlighted the complexities of diagnosis of underlying conditions where it is challenging to understand an individual's communication of their symptomatic experience.

The case was referred to the Southampton Local Safeguarding Adult Board to identify any learning for the system regarding how Adult H's communication difficulties, diagnosis of learning disability and behaviours, influenced the care he received. A Multi-Agency Partnership Review was commissioned.

FAMILY STATEMENT – NOVEMBER 2017

“A person with a severe learning disability and limited communication depends on carers, relatives and other healthcare professionals for all aspects of his health and welfare. My brother died from terminal cancer. His death was the likely outcome from the disease, but the length of time from early signs of illness until eventual death was protracted and very difficult for him and for those who loved him. The importance of listening to those involved in day-to-day care, those who have intimate knowledge of that person is paramount. Please always give us your attention.

Carers and relatives can often sense something is wrong but feel they may be worrying unnecessarily. If there is any doubt between challenging behaviour and/or a physical problem, please ensure there is not a medical issue. Medical interventions can be very difficult for those who lack understanding and mental capacity and this adds to distress.

From initial visits to his GP to his discharge from hospital, there was a lack of co-ordination and a slow response. This greatly impacted in his suffering. Some of those involved in his care were unused to dealing with a learning disability but there were many experienced professionals able to lead and co-ordinate delivery of care. Relatives should not have to undertake this co-ordination of different agencies.

The final weeks of my brother's life after discharge from hospital were not managed well, resulting in lack of identification of available services for palliative care. His support staff at his home were not confident in looking after someone with terminal illness and his subsequent death should have been comfortable and pain-free.”

Adult H's sister, November 2017

SCOPE AND PERIOD UNDER REVIEW

To establish the nature and extent of each organisation's contact and involvement with Adult H, chronologies will be requested from each agency involved with Adult H, to cover the time-period from 01/01/2015 to 03/01/2016.

The review will also consider other background information, what was known about Adult H, their life, and the circumstances of their death. The review will also be able to consider associated learning from other deaths of people with a learning disability, including learning from Safeguarding Adult Reviews.

AGENCIES INVOLVED

Southampton City Council	Adult Social Care
Southern Health NHS Foundation Trust	Community Learning Disability Team
University Hospital Southampton NHS Foundation Trust	Southampton General Hospital
Voyage Care	Domiciliary Care Agency

Following the initial communication with the GP, which took place prior to the commencement of the review, the GP practice has not been directly engaged in the review. This was due to processes taking place within NHS England. Despite this, a full and detailed Primary Care chronology was made available to the review team, together with an overview of system issues. The Clinical Commissioning Group provided this. The Adult H report will be shared with the GP practice and Learning Disabilities Mortality Review (LeDeR) Programme to enable learning to be shared as widely as possible.

PRINCIPLES

This multi-agency review was conducted in accordance with the principles for Safeguarding Adult reviews, laid out in the Care and Support Guidance to the Care Act 2014 (Department of Health, 2016). The following principles were published and shared with participants to the review:

- Non-blame
- Proportionality
- Awareness of risks of hindsight bias and outcome bias
- Incidents can provide the opportunity to learn and improve
- Focus on attitudes and culture
- Focus on system and teams functioning
- Not a re-investigation of incidents or performance

TERMS OF REFERENCE

- 1.1. To establish the circumstances and events surrounding Adult H's death.
- 1.2. To obtain and review Initial Agency Analysis Reports from the appropriate organisations to inform the review.
- 1.3. To draw on qualitative evidence in the form of information directly through conversations with Practitioners involved with Adult H.
- 1.4. Identify any stage within Adult H's care pathway where earlier decisions could have been made, including the confirmation of physical health diagnoses.
- 1.5. Ascertain the extent to which Adult H's learning disability and Autistic traits impacted on the management of physical health needs.
- 1.6. Identify how effectively the rapid deterioration of Adult H's health was managed.
- 1.7. To identify and consider emerging issues and themes throughout the investigation.
- 1.8. To highlight any good practice identified
- 1.9. To make recommendations to improve future practice; partnership working and the quality of life for service users.
- 1.10. To identify key issues for the Local Safeguarding Adults Board (LSAB) to consider
- 1.11. To provide the relatives of Adult H with the steps being taken to prevent any reoccurrence of events of a similar nature.

INVOLVEMENT OF FAMILY

The review benefitted greatly from the involvement and openness of family members of Adult H. The Lead Reviewer met with family members to draw on their experience of the care provided to Adult H, and their perception and experience of working with Health and Social Care Services in Southampton.

In keeping with the principles of the review, comments and views offered by close relatives were included as key evidence for the review along with documentary evidence and views of practitioners. The report author has therefore attempted to blend and embed the views of family members throughout the report, giving them the same weight as evidence and opinion obtained from records, practitioners, and organisations.

METHODOLOGY

The review methodology will draw on systems learning theory to evaluate and analyse information and relevant evidence gathered through the case of Adult H and relevant learning from research and other Reviews.

Agencies involved in the care of Adult H were asked to provide chronologies and an initial desktop analysis against the terms of reference.

Lead Reviewers have been supported by Adult H's family, and by Professionals Group made up of the Practitioners involved in Adult H's care.

EVALUATION OF PROFESSIONAL PRACTICE

That is, that the synopsis tells the story of the practice and response of the health and social care system – it is not a summary of the individual or their life, rather what their experience can tell the Safeguarding Adults Board about the way in which service operate.

The chronology provided by involved agencies notes that in as early as April 2013 Adult H had been difficulties with his physical health, a persistent cough and difficulties in swallowing. At this time, Adult H received a diagnosis of Hiatus Hernia following an investigatory x-ray. No further follow-up was thought necessary. This information was noted by practitioners involved in the review, but appeared to have been missed in 2015.

Adult H received their annual health check on 7th May 2015. The annual health check consisted of simple observations with very little narrative – it is completed through YES or NO answers to structured questions with very little free-text added.

In May 2015 further swallowing difficulties, and self-induced vomiting was noted, with up to 20kg of associated weight loss; this information was recorded by the Care Agency. During this time Adult H was supported by the care agency to see his GP. The GP record notes symptoms of pain on swallowing (over the last few days), and no enlarged lymph nodes. Adult H would not cooperate with further examination. Paracetamol was prescribed, with advice to return if there were no improvement. Adult H did return to the GP within two weeks, and pharyngitis was diagnosed and treated. Information was therefore recorded differently, by different agencies in relation to vomiting and weight loss.

In June 2015 family report, that swallowing difficulties and vomiting became more frequent. Adult H received a dental examination following advocacy by family. GP records indicate that five teeth were extracted under sedation. Pain on swallowing was identified and treated with

paracetamol. There was, perhaps, a missed opportunity to investigate the cause of pain on swallowing beyond a cursory physical examination to confirm lymph nodes not enlarged.

Between July 2015 and September 2015, investigations began into the cause of Adult H's pain and discomfort in swallowing. Referrals were completed to the Community ENT service, and to the Hospital for investigations. During this time, a theme emerged of reliance on the GP to expedite individual referrals to departments for investigation. Overall, Adult H presented to the GP on six occasions between May and October 2015. Presentations included judgements that vomiting and weight loss may be self-induced and "behavioural". During this time, Adult H also presented repeatedly to Accident and Emergency – something that was advised "*if Adult H had not eaten or drunk for 24 hours*". Based upon information from the review participants, and chronologies, the elective use of the Emergency Department appeared to be a strategy to overcome issues within the referral pathway. Adult H had previously been seen by Ear Nose and Throat specialists and discharged, with the advice to the GP to make an 'urgent' referral to upper gastro-intestinal surgical team.

The GP made this 'urgent' referral, which was graded as routine by the Hospital. At this time the symptoms may have indicated a fast-track referral under Two Week Wait would have been more appropriate. The GP was not aware that the referral had been graded as routine. It was noted that there are a number of different referral urgencies, for different conditions, and that these are decided locally, rather than mapped to a shared structure across the region. In general, additional complexities in the referral pathways can increase the risk of human factors in the incorrect urgency applied to any individual referral.

In October 2015, the GP liaised with the Hospital directly for the outcome of the urgent referral. A referral to gastroenterology through the two-week wait process was advised and completed. Miscommunication about Adult H's hospital appointments and poor planning complicated and delayed investigations further. In November 2015 Adult H underwent an operation, a stent was fitted and a biopsy taken. By the time, Adult H had been diagnosed with cancer he had suffered six months of pain and discomfort on swallowing, vomiting, and severe weight-loss. On 17th November 2015, Adult H was diagnosed with oesophageal cancer, which had spread and was terminal. Adult H passed away on 3rd January 2016.

The Review Team have given the circumstances of this case their careful consideration and concluded that although the system should have worked better in the diagnosis and coordination of care provided to Adult H, it would not have been possible to prevent the death of Adult H.

KEY LEARNING AND FINDINGS

Each organisation involved in the review was invited to submit an analysis of their involvement against the terms of reference above. In addition to conversations with family members, a practitioner event considered where practice or interventions could have been different, and how Adult H's learning disability may have affected the care, he received.

In order to enable the LSAB to "promote effective learning and improvement action to prevent future deaths or serious harm occurring again" (Department of Health, 2016) the analysis of key events in the case of Adult H is intended to focus on specific issues that provide an insight on the wider system.

In particular, a number of key findings have been identified which are explored below.

KEY FINDING 1: ANNUAL HEALTH CHECK

The Annual Health Check scheme is for adults and young people aged 14 or above with learning disabilities whom need more health support and who may otherwise have health conditions that go undetected. People with learning disabilities often have difficulty in recognising illness, communicating their needs and using health services. Research shows that regular health checks for people with learning disabilities can often uncover treatable health conditions.

The annual health check can prevent people with a learning disability from falling out of touch with services and can be used as an opportunity for a person to build confidence and develop trust with their GP and GP Practice. Done properly, the annual health check provides the person with a severe learning disability, their family, and carers, the chance to meet with the Practice team, become familiar with the clinical environment, and with clinical observation procedures. It can also enhance the GP's knowledge of their patient, for example to find out about the patient's understanding of healthcare, capacity to make healthcare related decisions, and the methods of intervention that are the most effective in providing investigation and treatment.

Adult H had experienced healthcare previously and in 2015 had an operation for the removal of a cyst from his hand, and emergency treatment having lacerated his hand after dropping a ceramic plate. Due to his cognitive impairment and lack of mental capacity to make decisions regarding his healthcare, it was evident that he needed additional support to receive healthcare. In addition to Adult H's familiarity with clinical processes, regular health checks would have given his GP, Practice staff, and his family and carers, the opportunity to assess what support Adult H needed and ascertain which interventions worked well.

Adult H did have an annual health check, completed on 7th May 2015, but this appears to have been very much a 'tick-box' exercise. The GP chronology contains a record of the health check which consists of a series of structured questions with YES/NO answers and very little opportunity for free-text narrative.

The Annual Health Check was also carried out as a single agency task and there is no evidence of input into this process by Adult H's family, formal paid carers, or Community Learning Disability Team. This is also a missed opportunity to enhance the multi-agency partnership around the individual.

Learning: Annual Health Check

The Annual Health Check should be an opportunity for a person with a learning disability to become accustomed to clinical environments and the experience of healthcare and for the GP and their Practice to get to know their patient.

The Annual Health Check would benefit from greater opportunity for involvement from family members, carer support, and by other agencies including health and social care.

Above all the Annual Health Check is an opportunity to review the person's history and uncover any underlying physical health problems that have not been recognised.

KEY FINDING 2: UNDERLYING CAUSES – ‘BEHAVIOUR’ OR PHYSICAL?

Around March 2015, Adult H began to present with self-inducing vomiting. In April 2015, he began to rub his cheek and grimace – indicating pain. A dental appointment revealed extensive tooth decay. This represents another situation where lack of regular check-ups failed to address a physical health issue that became acute. As a result of his tooth decay Adult H had five teeth extracted, something which would have been considered unusual – Adult H was 54 years old at the time.

One of the outcomes from this episode of care was that a formulation began to develop across agencies that Adult H’s swallowing difficulties and self-induced vomiting were attributed initially to his tooth decay and subsequently attributed to “behaviour” and learning disability. Assumptions about previous stress or emotional driven behaviour, his learning disability, and later the extent of his dental issues, all seemed to effect the seriousness and urgency of clinical responses to presenting issues. Adult H was demonstrating through behaviour – gesturing, grimacing, and self-induced vomiting that all was not well. Adult H, who previously enjoyed food, even seeking out cakes, was eating less and less, and experienced severe weight-loss.

From September 2015 a range of physical assessments were completed to rule out physical health needs. Adult H had a Panendoscopy (examination of the condition of areas including the larynx (voice box), upper trachea, the post-nasal space, and the oesophagus). Results came back normal and no underlying cause for Adult H’s behaviour was found. Adult H also underwent an Ear, Nose and Throat appointment; however, results also came back clear. Later in September Adult H underwent an extended dysphagia screening assessment. Results indicated that Adult H did not present with motor-based dysphagia. In October 2015, Adult H was diagnosed with an Oesophageal stricture, creating a food blockage, which explained the development of the self-induced vomiting behaviours. He underwent procedures to widen his oesophagus and a stent was inserted. In November 2015, Adult H was diagnosed with terminal cancer, with sites also located in the lungs and lymph nodes.

It was known that Adult H communicated pain and discomfort through gestures and grimacing. In this way, he had drawn attention to dental pain, which led to teeth extraction. Prior to thorough investigations, Adult H’s behaviour of self-induced vomiting was considered to be behavioural and linked to either his teeth extraction, or to his learning disability. Adult H was unable to communicate verbally which meant that professionals were reliant on his ‘behaviours’ as the main method of communication. In the diagnostic process, behaviours, such as self-induced vomiting, gestures, touching a part of the body, or putting a hand into the mouth, should be seen as a potential part of a person’s communication repertoire. In the case of Adult H, making assumptions or attributing meaning to behaviours without parallel investigation can result in discrimination or a failure to consider underlying causes.

There is a growing body of evidence to suggest that people with a learning disability have poorer health outcomes than the rest of the population (GMC, 2017) something that inadvertent discrimination may contribute to. It is important that people with a learning disability are not excluded from mainstream services to receive all their support from specialist teams. People with a learning disability should expect to be able to receive high quality care and treatment from mainstream services. Yet it has been recognised by the General Medical Council that people with a learning disability may face discrimination in the form of diagnostic overshadowing.

Working with individuals with different communication abilities can be challenging. Where an individual experiences a lack of mental capacity in relation to specific matters, or impaired communication, it is vital that all efforts are made to interpret an individual’s behaviours – to understand what a person’s behaviours are communicating. Medical investigations can help, but it is also important that clinicians are wary of making assumptions about behaviours or attributing them to an existing, known condition.

Diagnostic overshadowing:

Diagnostic overshadowing occurs when an individual has an established diagnosis of a major condition, and a tendency exists where subsequent problems are attributed to that condition, to the exclusion of co-existing, or underlying conditions. In the context of learning disabilities, this means, *“symptoms of physical ill health are mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person’s learning disabilities”* (Emerson and Baines, 2010). In order to avoid diagnostic overshadowing, Doctors are informed through their Guidance that they should:

- a) Adequately assess the patient’s conditions taking account of their history..., views and values; where necessary examine the patient
- b) Promptly provide or arrange suitable advice, investigations or treatment where necessary
- c) Refer a patient to another practitioner when this serves the patient’s needs.
(GMP, paragraph 15)

Learning: Underlying causes – ‘behaviour’ or physical

Great care should be taken in determining the underlying causes of particular behaviours. Medical history and the views of the person, their family, and other professionals can help clinicians understand what is occurring for the individual. It is vital that comprehensive assessments are completed to inform any hypothesis, and that relevant investigations (for physical causes and behavioural formulation) may need to be conducted ‘in parallel’ and should be undertaken in a timely way before fully embarking on a particular care pathway to the exclusion of others.

Adult H had limited mental capacity in key matters, and impaired communication. This introduced a risk of diagnostic overshadowing; a multi-disciplinary team approach could have made this risk explicit – including the measures put in place to mitigate against this.

KEY FINDING 3: MULTI-AGENCY WORKING AND COORDINATION OF CARE

Adult H was a gentleman with complex needs and multi-agency involvement. Over the course of the time period selected for this review the level of involvement and number of agencies working with Adult H increased.

During the first phase of the review period, Adult H was supported mainly by his family, by care agency staff and by his GP. At this time, care planning processes and an annual health check provided opportunities for partnership working, and holistic management of his needs. As Adult H's health began to deteriorate referrals were needed for investigation of his weight-loss and vomiting, and a referral was pursued to the Community Learning Disability Team. Even at this time, it is clear that family members acted as a catalyst for referrals, although it took the intervention of the Adult Social Care Quality and Safeguarding Team to successfully obtain involvement of the Learning Disability Team (the initial referral by a family member had focused on his inpatient care at the hospital for a hand operation). Once the referral had been received by the Learning Disability Team they were responded to promptly, on the day of referral – liaison by the Speech and Language Therapist with the GP was immediate.

During the second phase of the review, that leading up to the diagnosis of oesophageal cancer, difficulties in referral pathways continued and practitioners involved in the review accepted that members of Adult H's family had become the “conduit” between services – there was an over-reliance on family to facilitate appropriate care planning. Agency reports considered in the review confirm that throughout this phase multi-professional meetings, multi-disciplinary discussions, and Care Programme Approach¹ meetings happened regularly. Agency reports indicate that there was:

“close communication between staff members of the Learning Disability Team, the support provider, adult services team and primary care services, on a frequent basis.” And that *“there were a number of occasions when professionals came together to discuss Adult H and plan care.”* It was noted that challenges following the change of care provider were well managed, the new provider were described as being *“responsive from the outset”*.

It is also noted that the effectiveness of multi-agency communication was diminished by the limited ability and time resource that Adult H's GP had to engage in multi-agency processes. Poor communication was identified, a failure to return or answer messages, and lack of participation in Care Programme Approach meetings, or professionals meetings. One of the key themes emerging here was that of belief in the role of the GP as “gatekeeper” for services, leading to professionals feeling ‘blocked’.

There was a lot of activity being done by the GP that was not known or understood by the multi-agency partnership. This added to a perception that the GP was not engaged, or acting as a barrier to care, where in fact they were taking steps to ensure appropriate care and treatment was offered to Adult H. Efforts across agencies appeared to focus on facilitating communication with the individual GP. It was recognised by the partnership that there is significant pressure on GPs from high caseloads and an expanding role, but also a limited understanding or utilisation, by professionals of the role and potential for other members of staff at the Surgery to facilitate communication.

There was evidence of unilateral decision-making and a confusion about who was coordinating care for Adult H. The Care Programme Approach provides a framework for the delivery of services to people with a range of mental health problems or a learning disability. The Care Programme Approach includes the allocation of a Care Coordinator to facilitate review of service provision and communication between agencies.

¹ The Care Programme Approach (CPA) is a framework for how services are assessed, planned, delivered, coordinated and reviewed, for someone with mental health problems or a learning disability, with a range of complex needs and risks.

Despite this, and possibly as a result of the range of health and social care needs faced by Adult H, there was limited clarity about who should be coordinating the care for Adult H. There was no 'lead' professional identified by agencies involved in his care, and consequently no clear, single point of contact for Adult H's family.

Learning: Multi-agency working and coordination of care

Effective communication and healthy working relationships are an important part of good multi-agency practice. In the case of Adult H, whole-system communication was patchy, in particular the primary-secondary care interface was poor. This led to an inaccurate perception that referrals were stuck between the GP and others agencies. The complexity of the referral process, and varied referral-urgencies, may have compounded this.

There was a general and widespread recognition among participants in the review that the family of Adult H were pivotal in the raising of concerns and acted as a conduit between services. It was not clear who, if anyone, had overall responsibility for the coordination of Adult H's care, and the family were not given a clear, single point of contact.

KEY FINDING 4: END OF LIFE CARE – PATHWAYS AND PROCESSES

In November 2015, Adult H received a diagnosis of terminal oesophageal cancer.

Palliative care is for people living with a terminal illness where a cure is no longer possible. End of life care is an important part of palliative care for people who are nearing the end of life. End of life care aims to help people live as well as possible and to die with dignity.

There was evidence of appropriate discussion between Learning Disability Liaison Nurses at the General Hospital and the District Nursing service regarding palliative care and oncology follow up. Advice was also given regarding implementation of guidelines for staff supporting Adult H's pain management and sensory stimulation. The Physiotherapy Service also offered Hydrotherapy. The plan was to support Adult H at home for as long as possible before consideration of a move to a hospice.

Communication between the Hospital, family and multi-agency partnership with primary care services and the GP surgery continued to be problematic. There was a general lack of awareness across the partnership of the end of life referral pathways, which ultimately led to Adult H's family member attempting to make the referral herself. This communication issue extended to decisions about Cardiopulmonary Resuscitation (CpR). A 'Do Not Attempt CpR' form had been completed at the Hospital but it remained unclear whether a separate form would be needed for Community Services. It is crucial that across the system, professionals have a good awareness of the use of the unified DNACPR forms, and the implications for their use. Consistency is key.

Learning: End of life care – pathways and processes

It is apparent from the case of Adult H, that there was a lack of understanding by services who infrequently work with people at the end of their life, of the referral pathways and processes for end of life care.

The lack of a shared understanding about a clear pathway for end of life care, and disagreements about referral processes may have caused a delay in Adult H from receiving the right care and support, even once the diagnosis of oesophageal cancer was established.

A NOTE ON MENTAL CAPACITY

The Mental Capacity Act provides a statutory framework for the assessment of capacity and the ability to make particular decisions at a particular time. A person may be found to lack capacity to make a particular decision at the time it needs to be made if, because of, impairment in the function of mind or brain they are unable to make a decision by failing to be able to do any of the following:

- Understand the information relevant to the decision;
- Retain the information for long enough to be able to;
- Use and weigh-up the information as part of the decision-making process; or
- Communicate their decision, by any means.

Assessments were carried out on Adult H's ability to make decisions about care and treatment. They were regularly reviewed and family members and carers were involved in the assessment and best interests decision-making processes. Adult H is described as suffering from a profound learning disability. It is noted that he had severely limited communication skills. Adult H was assessed as unable to make decisions in all domains of the capacity assessment, because of his learning disability. Assessments of capacity in relation to care and treatment concluded that Adult H's learning disability meant that he had a severe cognitive impairment such that he was unable to understand, retain, use or weigh information and that additionally he was unable to communicate decisions.

It was noted that Adult H was able to understand only very basic information in the context of familiar routines, but that he was reliant on others for all aspects of decision-making about care and treatment. This placed Adult H in an extremely vulnerable position, where not only was he unable to communicate clearly his discomfort and pain – relying on others who knew him well to interpret his behaviours as communication – but that he was also wholly dependent on others to pursue best interests decisions on his behalf.

Section 1 of the Mental Capacity Act sets out five statutory principles that apply to any act done, or decision made, under the Mental Capacity Act. These include the principle that “*any act done, or decision made for or on behalf of a person who lacks capacity must be done, or made, in his best interests*” (S.1(5) MCA 2005). Section 4 of the Mental Capacity Act 2005 provides further guidance on best interests, outlining the steps that a person should take in determining what decision is in the person's best interests. This is often referred to as the best interests' checklist and requires decision-makers to:

- Encourage participation – do whatever is possible to permit and encourage the person to take part, or to improve their ability to take part, in making the decision
- Identify all relevant circumstances – try to identify all the things that the person who lacks capacity would take into account if they were making the decision or acting for themselves
- Find out the person's views
- Avoid discrimination – not make assumptions about someone's best interests simply on the basis of the person's age, appearance, condition or behaviour.
- Assess whether the person might regain capacity
- Consult others – in particular, anyone previously named by the person as someone to be consulted on either the decision in question or on similar issues, anyone engaged in caring for the person, close relatives, friends or others who take an interest in the person's welfare
- Avoid restricting the person's rights
- Weigh up all of these factors in order to work out what is in the person's best interests.

(Department of Health, 2007)

An important element of the best interests' checklist is the responsibility to consult others, of particular relevance in Adult H's case, this would have included:

- Anyone engaged in caring for Adult H
- Close relatives who take an interest in his welfare

Where a person has no one to support them in their decision-making (other than paid staff) and decisions involve serious medical treatment or long-term placement, an Independent Mental Capacity Advocate (IMCA) would need to be appointed. In the case of Adult H he was fully supported by close relatives who were able to support him in this regard, and offer consultation for the purposes of Best Interests – an IMCA was not needed.

There is evidence in the case of Adult H that practitioners were considering best interests and sharing information between themselves using local 'best interests' toolkits and paperwork. This was most effective, at the planning and decision-making stage, when considering support for inpatient admission for treatment at the General Hospital. Despite this process, however, some single-agency errors occurred in the execution of the decisions, disrupting Adult H's experience of treatment.

The provisions of section 4 MCA 2005 should have placed a legal duty on professionals engaged in decision-making about medical investigations and proposed treatment to have fully consulted Adult H's close relatives and involved them in the decision-making process. As noted in finding 3, Adult H's close relatives were often heavily involved in representing his views and in the coordination of care.

One systemic issue where learning can be captured is the appropriate role of close relatives in decision-making – this should have been to support Adult H and be consulted about his best interests. In fact, far too much responsibility appears to have been placed on close relatives to push for decisions to be made and to coordinate the actions and interventions of professionals.

Another area of learning is in the involvement of all agencies in the best interests' decision-making process. Where decisions are complex, agencies will often use 'best interests' meetings' as a way of sharing expertise, consulting widely, and agreeing the course of action to be followed. In the case of Adult H, such a process could have been considered to ensure that decisions about investigations and treatment were considered in wide consultation, rather than being made by individuals in isolation. It has already been noted in finding 3, that the absence of the GP practice diminished the effectiveness of communication, consultation, and the determination of Adult H's best interests.

It should be noted, however, that the Mental Capacity Act only applies to the decisions that fell within the jurisdiction of Adult H, or would have been expected to have been shared or collaboratively made. Best interest processes would have been applicable therefore to his consent to treatment, and to *his part* in agreeing which investigations should be carried out. The Mental Capacity cannot be used to 'take decisions away' from professionals when those decisions are within their remit alone, nor can it be used to create options that do not exist for a person who has capacity to make decisions for themselves.

Learning: Mental Capacity

Adult H had been assessed to lack capacity to make decisions about his care and treatment. Section 1 of the Mental Capacity Act 2005 (the principles) should have ensured that any decisions made on behalf of Adult H, were made following the 'best interests checklist'.

Through the best interests meeting process, there was an opportunity to have more fully involved all agencies (including the GP) and close relatives in making decisions about what investigations needed to occur and coordinating the planning and executing of these decisions. In the case of Adult H decisions were at times made without such consultation or without the adequate (or appropriate) involvement of close relatives.

MCA 2005 'Best Interests' decision-making processes were at best under-utilised. In the case of Adult H such processes could have been considered to ensure that decisions about investigations and treatment were considered in wide consultation, rather than by individuals in isolation.

OTHER FINDINGS FROM REVIEW PROCESS

Organisations were asked to review their own investigations and learning from the case of Adult H. A number of themes and trends were identified by agencies involved in the review. This section does not include learning that is by its nature attributable to an individual, or individual organisation and internally captured by organisational learning and governance processes. Where learning has implications, or is valuable to the wider system it has been captured in this section, and is summarised below.

Escalation processes:

"There is a need for organisations to support staff to be able to escalate issues in care delivery, or communication. Organisations may need to take responsibility for educating and empowering their staff to feel confident in challenging practice they have concerns about."

In the case of Adult H, members of staff were not clear on the process for escalation, nor of the urgency in which alternative resolution should have been sought. Agencies directed their energy to overcoming, or working around the perceived 'block' created by the GP role in gatekeeping onward services.

Members of staff who are not confident to challenge, or are not aware of how to escalate concerns, may not be able to be as strong an advocate for their service users. People who are unable to advocate for themselves may therefore face a delay in their voice being heard.

Recording:

"Recording of outcomes from appointments and meetings, especially in relation to health matters needs to be robust to ensure the accurate transfer and handover of technical information, agreed actions, and who is responsible for completing them."

Agencies were required to record and work from their own recollection and interpretation of actions from key meetings and information shared by third parties. Where key care planning or safeguarding meetings occur, they should be recorded and shared with participants to ensure communication, especially of technical information is clear.

RECOMMENDATIONS

No.	Finding	Summary	Impact	Recommendation	Lead Agency
1.	Annual Health Check	The Annual Health Check should be an opportunity for a person with a learning disability to become accustomed to clinical environments and the experience of healthcare and for the GP and their Practice to get to know their patient. It should not be simply a 'tick-box' exercise.	The purpose of the annual health check is to review the person's history and it provides an opportunity to uncover any underlying physical health problems that have not been recognised. This opportunity is missed when reviews are a tick box exercise.	The quality of annual health checks should be audited and reviewed.	Southampton City CCG
2.	Annual Health Check	The Annual Health Check would benefit from greater opportunity for involvement from family members, carer support, and by other agencies including health and social care.	Annual health checks completed in isolation and without wide consultation miss the opportunity to utilise the expertise of family members, formal carers, and professionals resulting in a less-good service.	GP Practices and Clinical Commissioning Groups should review their strategies to ensure annual health checks are not tick-box exercises and involve multi-agency working.	Southampton City CCG
3.	Underlying causes – 'behaviour' or physical	Great care should be taken in determining the underlying causes of particular behaviours. Medical history and the views of the person, their family, and other professionals can help clinicians understand what is occurring for the individual.	The risk of diagnostic overshadowing is well documented. Should this occur there is an enhanced risk of failure to identify serious co-existing or underlying problems. This may ultimately be a factor in the premature deaths of people with a learning disability.	GMC Guidance on diagnostic overshadowing should be re-issued to Board members and GPs.	LSAB
				A study of culture of multi-disciplinary practice, and awareness of diagnostic overshadowing could help agencies to work together to recognise when the risk of diagnostic overshadowing is elevated, and be explicit about measures taken to avoid it.	To be considered by the LSAB

No.	Finding	Summary	Impact	Recommendation	Lead Agency
4.	Underlying causes – ‘behaviour’ or physical	It is vital that comprehensive assessments are completed to inform any hypothesis, and that relevant investigations (for physical causes and behavioural formulation) may need to be conducted ‘in parallel’ and should be undertaken in a timely way before fully embarking on a particular care pathway to the exclusion of others.	<p>Early assumptions about underlying causes of behaviours, or a failure to correctly identify what a person is trying to communicate can lead to the wrong treatment pathway being followed – both physical investigation, or behavioural interventions.</p> <p>This can lead to delays in diagnosis of co-existing conditions, or unnecessary investigations which may be distressing or uncomfortable. Good multi-agency working and sharing of expertise is essential.</p>	Parallel investigation pathways and guidance should be reviewed / formulated across the partnership. This may need further exploration as a practice area.	Southampton City CCG
5.	Learning: Multi-agency working and coordination of care	Effective communication and healthy working relationships are an important part of good multi-agency practice. In the case of Adult H, whole-system communication was patchy, in particular the primary-secondary care interface was poor. This led to an inaccurate perception that referrals were stuck between the GP and others agencies. The complexity of the referral process, and varied referral-urgencies, may have compounded this.	Individual clinicians and GPs become more vulnerable to poor working relationships, misperceptions of role, responsibility, or activity. This can result in less effective patient-advocacy, or human factors leading to poor clinical outcomes.	<p>A communication plan should be adopted for individual’s with complex conditions, impaired mental capacity, or communication.</p> <p>Explicit guidance on when individuals may be supported by a ‘second opinion’ should be reviewed or formulated.</p> <p>This needs to be linked to communities, families and carers</p>	<p>All health providers including CCG, (STP)</p> <p>Could this link to the Hants Health Sub group work re Adult C</p>

No.	Finding	Summary	Impact	Recommendation	Lead Agency
6.	Learning: Multi-agency working and coordination of care	There was a general and widespread recognition among participants in the review that the family of Adult H were pivotal in the raising of concerns and acted as a conduit between services. It was not clear whom, if anyone, had overall responsibility for the coordination of Adult H's care, and the family were not given a clear, single point of contact.	In cases where a number of agencies are involved, each with particular specialities, the lack of an identified point of contact or 'Lead Professional' can leave families vulnerable to becoming the unintentional conduit between services. This can place additional burdens on families to undertake a professional role in addition to a caring one.	Multi-agency care planning processes, whether medical, care management, or Care Programme Approach, should be explicit to include the identification of a 'Lead Professional'.	4LSAB group to consider
7.	End of life care – pathways and processes	It is apparent from the case of Adult H, that there was a lack of understanding by services who infrequently work with people at the end of their life, of the referral pathways and processes for end of life care.	Services may be less well coordinated, or opportunities missed for good end of life care. There can be limited opportunities to address mistakes, and people at the end of their life may suffer unnecessarily.	Pathways, referral processes, should be clear and accessible. Good coordination is important, and health professionals involved in the identification or life-limiting illnesses may be best placed to educate other professionals.	Southampton City CCG via End of Life Care Strategy group
8.	Mental Capacity	MCA 2005 'Best Interests' decision-making processes were at best under-utilised. In the case of Adult H, such processes could have been considered to ensure that decisions about investigations and treatment were considered in wide consultation, rather than by individuals in isolation.	Decisions made in consultation, drawing on all available expertise offer people better outcomes, and more personalised best interests outcomes.	Organisations need to ensure that the best interests requirements of the MCA 2005 are being fully implemented – in particular the genuine and meaningful consultation of close relatives and interested persons in the individual's care.	4LSAB to lead alongside NHS England Wessex Safeguarding Programme

No.	Finding	Summary	Impact	Recommendation	Lead Agency
9.	Other Findings	<p>There is a need for organisations to support staff to be able to escalate issues in care delivery, or communication.</p> <p>Organisations may need to take responsibility for educating and empowering their staff to feel confident in challenging practice they have concerns about.</p>	<p>Members of staff who are not confident to challenge, or are not aware of how to escalate concerns may not be able to be as strong an advocate for their service users. People who are unable to advocate for themselves may face a delay in their voice being heard.</p>	<p>Escalation processes across the partnership should be clear and explicit, especially in key areas such as Health, Social Care, statutory board members and for care quality. These should be easily available electronically and on the LSAB website.</p>	4LSAB Policy Group
10.	Other Findings	<p>Recording of outcomes from appointments and meetings, especially in relation to health matters needs to be robust to ensure the accurate transfer and handover of technical information, agreed actions, and who is responsible for completing them.</p>	<p>Inaccurate or incomplete recording of actions and technical information can lead to miscommunication and misunderstanding. It can undermine good multi-agency working.</p>	<p>Summaries of key meetings (CPA, health and safeguarding), interventions and outcomes and actions should be produced by the Chair of the meeting and shared appropriately with agencies. Non-specialist professionals should not have to rely on their own interpretations – especially in relation to technical, medical, or complex matters.</p>	Southampton City CCG Quality Team

FURTHER STEPS AND ACTION PLANS

The recommendations have been formulated against the learning identified in this review. The LSAB is encouraged to use these as the foundations of a multi-agency action plan. There will be a number of potential solutions or actions that may address the recommendations and learning, and these should be considered across all intervention domains. Specific actions may include the need for communications, amendments to, or creation of, policy and guidance, or may have a training element.