Kirklees Safeguarding Adults Board

Partners in preventing abuse and neglect

ADULT O

A SAFEGUARDING ADULT REVIEW (SAR)

A review commissioned by Kirklees Safeguarding Adults Board (KSAB)

Publication date Monday 28th February 2022

Contents

1 Introduction

1.1 This Safeguarding Adults Review (SAR) has been commissioned in respect of Adult O, a twenty one year old female with complex health needs, who sadly died on the 24 October 2020.

1.2 Adult O's case was referred into the Kirklees Safeguarding Adults Board (KSAB) SAR Subgroup in November 2020, and it was agreed that a SAR should be commissioned, however at the time there was an on-going criminal investigation, so this needed to be concluded first. It was confirmed in December 2020 that the criminal investigation had concluded, and agencies were asked to provide a scoping document detailing their involvement with Adult O. At the end of January 2021, the scoping documents were received, and the SAR Subgroup agreed the methodology to be utilised for Adult O's SAR. This was then ratified by the Chair of the KSAB in March 2021.

1.3 KSAB commissioned this SAR in accordance with the Care Act (2014)[1] because there were concerns regarding how effectively agencies worked together to safeguard Adult O.

1.4 The aim of this review is for agencies to reflect and learn lessons about the way they worked both individually and collectively to safeguard adults at risk, with similar circumstances to Adult O. This SAR will not seek to apportion blame to any individual or agency, instead, the focus will be on identifying lessons in a transparent way, so that local actions to address the issues can be identified and collaboratively taken forward.

1.5 The review process included a practitioner learning event that took place virtually on Microsoft Teams (due to the Covid-19 pandemic) on the 16 September 2021. The information obtained from the learning event was incorporated into the analysis of this report.

1.6 At the time of her death in October 2020, Adult O had been living at her family home and was cared for primarily by her mother (who will be referred to throughout the report as 'Adult O's mum'). Adult O had complex health needs from birth, including

[1] Legislation that sets out the Local Authority duties for adults with care and support needs

cerebral palsy[2], scoliosis[3], blindness, epilepsy[4], quadriplegia[5] and she also had a profound learning disability.[6]

1.7 As a child, Adult O attended a special education school, and it appears that the educational setting promoted reasonable access to health services and provided an easily accessible environment for her to be seen.

1.8 Although, there were also some challenges in regard to Adult O (as a child) being taken for external health appointments, and this will be further detailed in the analysis of this report.

1.9 In July 2018 (when Adult O was nineteen), Adult O left school and after that time her contact with health and social care services was minimal. Adult O did not go through a formal transition process from children to adult services, which she should have had in accordance with the National Institute for Health and Care Excellence (NICE) guideline [NG43] for 'transition from children's to adults' services for young people using health or social care services' (2016)[7].

1.10 Adult O had previously been admitted to hospital in 2017 and 2018 and treated for sepsis[8] which she successfully recovered from and returned home. On the 22 October 2020, Adult O's mum contacted her General Practitioner (GP) because she was concerned about Adult O's physical health. Consequently, Adult O was admitted to Huddersfield Royal Infirmary (Calderdale and Huddersfield Foundation Trust (CHFT)) the same day, and a sepsis pathway[9] was triggered.

[2] A lifelong condition that affects movement and coordination
[3] Where the spine twists and curves to the side
[4] A neurological disorder causing seizures (fits)
[5] Paralysis of all four limbs
[6] Severe learning disability that significantly affects a person's ability to communicate and be independent
[7] https://www.nice.org.uk/guidance/ng43

[8] When the immune system overreacts to an infection and begins to damage the body itself, leading to organ failure and in some cases, death
[9] Part of the Sepsis Trust's recommended approach to diagnosing and treating sepsis

1.11 In accident and emergency (A&E), a safeguarding alert (in accordance with Section 42[10] of the Care Act (2014)) was raised. The alert was made following significant concerns over Adult O's physical condition, she was noted to have a grade four necrotic pressure sore[11] to her left heel, sores to her sacrum, hip, and genital area. Adult O's mum told staff that she was the main carer for Adult O, and that she did not require any additional support at home.

1.12 Sadly, on the 24 October 2020 Adult O died in hospital, her formal cause of death was given as sepsis[12] and bronchopneumonia[13].

2 Terms of Reference (ToR)

2.1 A chronology of key events were examined from 1999 (when Adult O was aged two years old) and ending in October 2020, when Adult O passed away.

2.2 The specific terms of reference for this review were:

- To analyse if there were missed opportunities by agencies, particularly in ensuring that Adult O's mum was able to fully meet Adult O's needs and was able to seek appropriate support when needed.
- The appropriateness of arrangements that were in place for Adult O at the point of her transition from children to adult services.
- How well risks were identified, assessed, managed and responded to (timeliness and interventions at key points) and to determine how effectively agencies worked together, shared information and responded in a coordinated way at key points.
- To identify what prevented action being taken when opportunities arose to safeguard Adult O.
- To examine to what extent the Mental Capacity Act (MCA, 2005)[14] and best interest decisions were considered at key points for Adult O and her carers.

[10] Where the Local Authority must make enquiries if they receive a report regarding an adult at risk of abuse, a Section 42 enquiry establishes whether any action needs to be taken to prevent or stop abuse
[11] The most severe pressure damage and where the tissue surrounding the sore becomes necrotic (meaning the tissue has died due to lack of blood and oxygen)

[13] A type of pneumonia causing inflammation of the lungs.
[14] Legislation that safeguards people who may lack mental capacity, from the age of sixteen

3 Partners involved in the review

3.1 The following agencies and their commissioned services participated in this review and formed the SAR panel and learning event:

3.2 Table one:

Agency	Services provided to Adult O
Kirklees Council Children's Social Care including Safeguarding Children's Partnership	Social Care Services when Adult O was a child.
Kirklees Council Adult Social Care (All Age Disability)	Social Care services, had input with Adult O from 2017 when she was an adult.
Nutricia Enteral Services	Overseeing Adult O's nutritional needs in the community
NHS Kirklees Clinical Commissioning Groups (CCG's)	Commissioners of local health services.
Colne Valley Group Practice	Primary Care (GP) services.
Yorkshire Ambulance Service (YAS)	In October 2020 took Adult O to hospital via ambulance.
Calderdale and Huddersfield Foundation Trust (CHFT)	Adult O was seen by CHFT in paediatric and adult services, as an in-patient and out-patient and by community teams.
Locala	Provided NHS adult therapy services including home enteral nutrition (HEN), dietician, dentist and continence services.
Accessible Homes Team	Occupational Therapy (OT) and provision of manual handling equipment

3.3 All agencies were required to submit a scoping document and chronology that encouraged early individual reflective learning. The chronologies and learning were then combined, and the Author, Chair and SAR panel identified further areas that needed to be explored by all agencies involved.

3.4 This review was overseen by the Kirklees Safeguarding Adults Board (KSAB) Subgroup.

4 Practitioner Learning Event

4.1 The learning event was an opportunity for the practitioners who were involved with Adult O and her family, to collaboratively reflect and identify learning in a safe and transparent space.

4.2 The important information obtained helped the Author and Chair to understand individual and collective learning at a greater depth, as well as identifying good practice.

4.3 Due to the Covid-19 pandemic, the learning event took place virtually and there was full engagement from all agencies.

4.4 The Author devised and presented a key event and thematic chronology after collating all agency timelines, this was presented using a PowerPoint presentation and the practitioners were asked to reflect on three key questions;

- What went well?
- What did not go so well?
- What should have been done differently?

4.5 At the end of the event the agencies were then asked to provide feedback on:

- One key learning point for their agency
- What needed to change to improve future practice
- An area of good practice

4.6 The answers to these questions have been incorporated into this report.

4.7 The learning event was successful because of the practitioners willingness to be open, reflective and supportive of each other. On behalf of the KSAB, huge thanks are given to those practitioners for making the event successful.

5 Adult O's family

5.1 On behalf of KSAB the Author and Chair of this review would like to express their sincere condolences to Adult O's family.

5.2 In August 2021, the Author and Service Manager for the KSAB met with Adult O's mum at her home address. Adult O's mum was happy to be involved in the SAR process and provided very important information in regard to who Adult O was as a person.

5.3 Adult O's mum also provided insight into her life as Adult O's carer and described the input she received from health and social care services, it was evident how much she loved her daughter and described the close bond they had. Adult O's mum advocated on behalf of the family.

5.4 Adult O's mum explained that she liked to care for Adult O herself and said that help from services was much better when Adult O was a child. Adult O's mum explained that when Adult O left school (at the age of nineteen) she no longer knew who to turn to for support, and if she needed anything she would contact her GP.

5.5 Adult O's mum openly explained that she had experienced long term anxieties about health environments, particularly in hospital and dental settings. Adult O's mum said that services were aware of this, but she did not get additional support to help manage her phobia.

5.6 Family visit by KSAB Service Manager and Author on 26/11/2021 Adult O's mum agreed the content on the report and did not wish to add anything further.

6 Author of the report

6.1 The Independent Author of this report was Lorna Warriner.

6.2 Lorna is a Mental Health Nurse (RMN) and has held her registration with the Nursing and Midwifery Council (NMC) since 2006.

6.3 Lorna has expertise in complex health commissioning and adult safeguarding, she has a specialist interest in the SAR process and is passionate about the promotion of learning and reflection to improve systems and practice across the health and social care system.

6.4 Lorna wishes to thank the KSAB and Adult O's family for trusting her to tell Adult O's important story.

7 Timeline of important key events

7.1 The following key events have been identified as important to read in context of this full report, the detailed analysis of these key events will be explored further in the analysis section.

2005

7.2 It was recorded by Children's Social Care that Adult O's mum had some anxiety regarding seeing health professionals, and that she needed some support to take Adult O to the dentist, because she was too frightened.

2009

7.3 Information recorded within Children's Social Care records indicate that Adult O was not being taken to Consultant Paediatric clinic appointments (last seen in 2008).

7.4 A Children's Social Worker spoke with Adult O's family because she was concerned about Adult O's dental hygiene, and non-attendance at appointments.

7.5 The school documented that Adult O's weight was more stable in term time when she was having high calorie foods in school, but her weight would drop again in school holidays.

2011

7.6 A school worker contacted Children's Social Services regarding a number of concerns regarding weight loss, poor personal care and Adult O missing dental appointments.

2012

7.7 A Children's Social Worker discussed Adult O's case in supervision because she was concerned that Adult O was not being taken to dental appointments.

7.8 Adult O was discharged from the dental hospital because of numerous missed appointments.

2013

7.9 Adult O had a pressure sore to her hip due to her wheelchair not being appropriately fitted, a new mould was made and the sore heeled.

2014 (aged fifteen/sixteen years old)

7.10 The school was concerned that Adult O's mum was not taking her to health appointments. Safeguarding advice was sought at the time (from the Local Authority), but it was deemed not to meet the threshold of a safeguarding enquiry and the school were asked to monitor.

7.11 The Consultant Paediatrician wrote to Adult O's family to say that he was disappointed that he had not seen Adult O in clinic. The Consultant Paediatrician wrote to the GP to ask why it might be that Adult O was not attending.

2015

7.12 Adult O was not taken to a school dietetic appointment, there was no cancellation or reason given.

2016 (aged seventeen/eighteen years old)

7.13 The Consultant Paediatrician wrote to a CHFT Learning Disability Matron[15] and to the GP to request commencing transition from children to adult services. According to the records, this was not responded to and the Consultant Paediatrician sent a further letter to the GP saying that Adult O's transition would be complex. There is no evidence within the records that this was responded to.

7.14 Adult O had a pressure sore due to her sleep system rubbing, this was reassessed, changed and the pressure sore heeled.

2017

7.15 Adult O had an acute admission to CHFT hospital following a chest infection and subsequent diagnosis of sepsis. Adult O's mum contacted the GP due to cold symptoms and shortness of breath, Adult O spent eight days in hospital. The Learning Disability Matron at the hospital recorded that the School Nurses had reported that Adult O's mum had a phobia of hospitals.

2018

7.16 Adult O's mum declined a carers assessment[16] offered by Adult Social Care, but Adult O was referred to a day centre for two days a week (at the request of Adult O's mum). This offer was subsequently declined by Adult O's mum because the cost was believed to be too expensive. Adult Social Care involvement ceased at this point.

7.17 Adult O was not taken to a paediatric epilepsy clinic appointment, so was referred back to her GP and she referred to the adult epilepsy service.

[15] A community senior nurse who works closely with the GP and the patient to plan care
[16] Statutory right under the Care Act (2014) for those who are informal (not paid) carers

7.18 Adult O continued not to attend the Consultant Paediatric clinic appointments, so was referred back to the GP.

7.19 Adult O's mum contacted the GP because Adult O had become unwell with a chest infection, the GP was concerned that Adult O's mum may not have been recognising the signs of sepsis, and an ambulance called. In hospital, it was noted that Adult O had high sodium levels[17] which seemed unusual, and it was queried how long she had been dehydrated for. Adult O was subsequently diagnosed with pneumonia and an acute kidney injury[18]. In response to this acute admission the GP met with Adult O and her mum (when discharged), and verbal advice given on how to catch and treat early in the event Adult O became unwell again.

2019

7.20 Adult O did not attend the adult epilepsy clinic (arranged in 2018) so Adult O was discharged back to the care of her GP. Subsequently, this was arranged for August 2019, but Adult O was not taken to that appointment.

7.21 The GP identified that Adult O had not been collecting her epilepsy medication for over a year and realised that Adult O had not been receiving annual learning disability health checks. Adult O was added to the GP learning disability register and completed a medication review.

7.22 Adult O's mum cancelled a Locala Dietician home visit because Adult O was not well (Adult O was last seen by a Dietician in 2018). Subsequently, further appointments were made but were cancelled due to Adult O or her mum not being well.

7.23 The Locala continence service reviewed Adult O at home and tasked the GP to test Adult O's urine as there appeared to be a strong smell. Adult O's mum was advised to increase fluid intake and to take a urine sample into the GP surgery. The urine sample was not taken to the surgery and the GP did not follow this up.

[17] When the sodium in a person's blood is too high often associated with insufficient fluid intake
[18] Sudden damage to the kidneys causing them not to work properly

7.24 Adult O was seen at home by the GP after Adult O's mum contacted the surgery concerned that Adult O was unwell. Antibiotics were prescribed due to a chest infection, advice was given about what to look for if Adult O's condition deteriorated, but no further follow up was arranged.

2020

7.25 Locala Dieticians attempted to contact Adult O's mum on several occasions to arrange a home visit, but there was no response to calls or letters. The Dietician asked a Dietetic Assistant to contact Adult O's GP surgery to determine if they had any concerns about seeing Adult O. The GP surgery advised that Adult O had last been seen in September 2020 by a GP, and no further action was taken.

7.26 Adult O had her first annual learning disability health check completed by the GP (August 2020).

22 October 2020:

7.27 Adult O's mum contacted the GP due to concerns that Adult O was unwell, a sepsis pathway was triggered, and an ambulance took Adult O to hospital. The GP had safeguarding concerns because this was the third incident of sepsis in three years, and Adult O had a necrotic pressure sore to her heel. The GP shared her concern with the hospital and had planned to share her concerns with the Local Authority safeguarding service if this was not initiated by the hospital.

8 Detailed analysis in response to the Terms of Reference (ToR)

8.1 As a result of the information shared and reviewed, the following responses to the ToR have been identified:

To analyse if there were missed opportunities by agencies, particularly in ensuring that Adult O's mum was able to fully meet Adult O's needs and was able to seek appropriate support when needed.

8.2 Throughout this report, the Author reflected on how challenging it can be to care for a child with complex needs, and that it becomes more complex when the child enters adulthood. The content of this report is written in the spirit of support for Adult O's mum, and appreciation for how long she cared for Adult O as her primary carer.

8.3 As a child, Adult O was registered as a 'child in need,' which meant that she needed support by Children's Social Care services because of her disabilities. This meant that she was expected to require services and support in order to have access to the same health and development opportunities as other children her age.

8.4 There is evidence in as early as 2009 (when Adult O was aged ten/eleven years old) that concerns were being shared by the school to Children's Social Care regarding Adult O not being taken to external health appointments. At the time, particular concern was highlighted regarding Adult O not attending dental appointments.

8.5 In August 2012 (aged thirteen years old), Adult O was taken to a dental appointment, after persistent encouragement by the allocated social worker at the time. It was identified at that appointment that Adult O had a number of cavities[19] and that she would require anaesthesia[20] to receive treatment.

8.6 At that time, Adult O was waiting for an appointment to receive hip surgery so it was considered whether she could have the hip surgery and the dental treatment together.

8.7 Later in October 2012 (Adult O was still waiting for hip surgery), Adult O was seen by a Dentist, and it was reported that her dental health had improved following dietary advice given in August. Further dental appointments were made but Adult O was not taken to them, and in February 2012 a Dentist recorded that dental appointments should be left until Adult O had received the hip surgery. There is no evidence to suggest this was communicated with any other agency.

8.8 In July 2015, the Consultant Paediatrician requested a dental appointment for Adult O and in response the dental service sent a letter to Adult O's mum asking her to make

[19] Permanent damaged areas in the teeth that develop into tiny openings/holes
[20] A state of controlled unconsciousness often used for medical surgery

contact. No further contact was made with the dental surgery meaning Adult O was last physically seen by a dentist in October 2012.

8.9 There is plenty of documented evidence within Adult O's records (both when Adult O was a child and as an adult) that Adult O's mum had a phobia regarding medical environments. However, from a collective review of the chronologies it is not clear this was recognised by agencies with no detail of what support was offered to help her mum understand and support Adult O's needs.

8.10 Reasonable adjustments could have included services attempting to arrange all of Adult O's medical appointments on the same day, and in the same place. Another example could have been consideration of a personal assistant (PA) to be commissioned and solely responsible to take Adult O to her appointments.

8.11 In June 2013 (Adult O was aged fourteen years old), Adult O had a pressure sore[21] to her hip which was thought to be due to her wheelchair not fitting correctly, this healed with reassessment and oversight from the children's community nursing service.

8.12 In May 2016 (Adult O was aged seventeen years old), Adult O had another pressure sore which was thought to be due to her sleep system[22] rubbing, this also healed successfully after being fitted for a new system. There is no evidence that during Adult O's life her mum was given support and advice in regard to supporting Adult O to maintain good tissue viability, and how to recognise any future signs and symptoms of pressure damage.

8.13 In November 2017 (Adult O was aged nineteen years old), Adult O had spent eight days in hospital and was treated for sepsis. Adult O was admitted to hospital after her mum requested a GP home visit as Adult O was presenting with cold symptoms. There is no evidence in records that advice was given to Adult O's mum at the time to help her identify any future signs and symptoms of sepsis.

8.14 In July 2018 (Adult O was aged nineteen years old), Adult O was admitted to hospital again and a sepsis pathway was triggered. At the time, the GP was concerned that Adult

[21] Damage to the skin and underlying tissue
[22] To assist with good postural management at night

O's mum may not have been recognising the signs and symptoms of sepsis and noted that her presentation was the same as in November 2017.

8.15 In August 2018, the GP followed up these concerns at a face-to-face appointment with Adult O and her mum, and the GP provided advice regarding catching and treating infection early, in the event that Adult O became unwell. Whilst this is good that the GP provided this verbal advice, more practical support could have been given such as providing Adult O's mum with a thermometer[23] and an accessible carer/family friendly sepsis screening tool[24].

8.16 In August 2019 (when Adult O was aged twenty years old), an Epilepsy (adult) Specialist Nurse contacted the GP practice to say that Adult O had not been taken to a clinic appointment. After being informed of this the GP identified that Adult O had not had any prescriptions collected for her epilepsy medication for over a year, and that she was not registered to have annual learning disability health checks[25]. It has collectively been reflected that this was a missed opportunity to seek safeguarding advice relating to Adult O not being seen in the epilepsy clinic, and not having her prescribed epilepsy medication for over a year.

8.17 Adult O's epilepsy medication was classed as a 'critical' medication meaning that it should not have been omitted without medical oversight, as it had the potential to cause harm if not taken. It has not been possible to understand why the GP practice did not realise that a critical medication had not been requested for over a year, and this has been individual learning for the practice.

8.18 In September 2019 (when Adult O was aged twenty years old), Adult O was seen at home by a GP and she was diagnosed with a chest infection. The GP documented that Adult O was at high risk of deteriorating and antibiotics were prescribed.

8.19 However, after seeing Adult O the GP did not arrange any further follow up. The GP Safeguarding Lead at the learning event said this was a missed opportunity given Adult O's previous occurrences of sepsis and comorbidities. Also, a NEWS2 tool[26] was not

[23] To monitor temperature
[24] https://sepsistrust.org/wp-content/uploads/2018/06/Community-carers-NICE-Final-2.pdf

[25] Yearly health checks specifically for people with a learning disability
[26] https://www.rcplondon.ac.uk/projects/outputs/national-early-warning-score-news-2

completed at that appointment, which should have been as a nationally recognised evidence based clinical tool to identify acutely unwell patients. Again, this was individual learning for this GP practice during this SAR process.

8.20 Adult O should have had annual health checks from the age of fourteen, it appears that due to an administrative coding issue the GP practice did not put Adult O onto their learning disability register. This was a missed opportunity to assess and support Adult O and her mum in relation her health needs.

8.21 Adult O's mum was offered a carers assessment in August 2018 (Adult O was then nineteen years old) by Adult Social Care. Adult O's mum declined this assessment but there does not appear to be any further attempts to reoffer, or advice given to Adult O's mum in regard to alternative support available. Adult O's mum told the Author and Service Manager she did not know how to seek a carers assessment if she needed one.

The appropriateness of arrangements that were in place for Adult O at the point of her transition from children to adult services.

8.22 After Adult O left school a referral was made to Adult Social Care which was received in July 2018 (Adult O was aged nineteen years old). This referral was made by Adult O's mum who was asking for access to day care services.

8.23 Prior to this referral, Adult Social Care were not involved in Adult O's care and there had not been a formal transition process from children to adult services. At the learning event an Adult Social Care representative said that the reason for this was because Children's Social Care (Children's with Disabilities Team) had closed Adult O's case in 2012 (Adult O was aged fourteen) because they considered that she did not have social care needs. This in fact was not the case, but rather that Adult O's mum declined the offer of an assessment for a care and support package in their own home, as she wanted to care for Adult O herself.

8.24 This closure of the case is important because it meant that a transition process was not initiated with Adult Social Care. At time of Adult O's transition to adulthood, and also at the time of writing this report, the transition process within Kirklees Council

(providers of social care) is only available and commissioned for young people who receive a health or social care funded service.

8.25 To rectify this issue the practitioners at the learning event proposed that consideration needed to be given to how a transition pathway is commissioned for all young people with disabilities, irrespective of whether they are in receipt of a health or social care package.

8.26 In May 2016, the Consultant Paediatrician wrote to a CHFT Learning disability Matron and to the GP to start the transition to adult services, Adult O was aged seventeen at the time. These letters had been received but a formal transition process was not initiated.

8.27 A further letter was sent by the Consultant Paediatrician to the GP in December 2016 (Adult O was aged eighteen by then), stating that he thought Adult O's transition to adult services would be complex and he wanted to discuss this. However, it appears that this discussion did not take place.

8.28 The fact that Adult O did not go through a formal transition process is identified as one of the root causes to her not having the appropriate health and social care oversight as an adult. When Adult O was at school, there was continued monitoring and oversight opportunities as the school, to an extent, took some responsibility for alerting and informing services about Adult O's access to health and social care services. However, when Adult O left school the oversight monitoring was lost, and she only had her GP as lead coordinator of her care.

8.29 The aforementioned NICE guidelines for transition recommend that the process should start at the age of nine, and fourteen at the latest. There is a responsibility for both children and adult services to work in an integrated way (as set out in the Care Act 2014) to ensure good communication, high quality of care, and better outcomes for young people going through transition. There is no evidence that this happened in Adult O's case.

8.30 In accordance with the NICE guidelines Adult O and her mum should have known what support was available for them, and should have been fully involved in the planning, coordination and implementation of the care and support on offer.

8.31 Transition processes should be multiagency led but there should also be an identified 'named worker.' A named worker should have been identified from one organisation (the agency best placed) and their responsibility would have been to lead on the transition process, and to help Adult O work towards more independent living as an adult.

8.32 The NICE guidelines also state that where a young person may not be eligible for statutory social care services, the young person and their families/carers should be given accessible information on how to find alternative support. It is important to note that Adult O was eligible for social care support, but this was declined by Adult O's mum. Regardless of whether she was in receipt of services, alternative and accessible information should have been given to Adult O and her family.

8.33 In conclusion, the lack of a transition process for Adult O meant that the basic foundations of her health and social care support had not been built. Professionals did not invest enough time and resource into developing a relationship with Adult O and her mum. This was essential to ensure they were both supported, and that Adult O's mum had the required tools to care for Adult O's needs when she became an adult.

How well risks were identified, assessed, managed and responded to (timeliness and interventions at key points) and to determine how effectively agencies worked together, shared information and responded in a coordinated way at key points.

8.34 As a child and adult, there were missed opportunities by all agencies to identify that Adult O was at risk of her health and social care needs being met.

8.35 Adult O should have had social care reviews from 2016 (when she turned eighteen), but as already detailed, her first review was in 2018, which was actually instigated by her mum. Adult Social Care responded to the referral and an offer of day care was given, but this was declined by Adult O's mum due to the cost. After this, Adult O's case was closed again to Adult Social Care and no further exploration attempted to understand and consult Adult O regarding her financial situation.

8.36 With Adult O having previous episodes of sepsis, this did not necessarily indicate that she would develop it again, but it may have been preventable. There was documented

evidence within the GP records in 2018 that Adult O's mum may not have been recognising the signs and symptoms of sepsis. It was agreed at the learning event (and already reflected in this report), that more could and should have been done to offer practical advice and support[27].

8.37 Given Adult O's complex physical health it is surprising that she was not known to an adult community learning disability service, or, under the care of other secondary community services.[28] The agencies involved reflected that this was due to Adult O being closed to services as a young person, so onward referrals were not made when she became an adult.

8.38 In 2018 (Adult O was aged nineteen years old), Adult O had some input from adult therapy services provided by Locala[29], in the form of a Dietician[30]. After this one appointment, a further three follow up home visits were cancelled by Adult O's mum and she was not seen again.

8.39 Adult O was also under the care of Nutricia[31] when she was a child and adult, and they provided support in regard to Adult O's gastrostomy tube[32] and nutritional feeds[33].

8.40 Adult O was last seen at home by Nutricia in May 2018 (Adult O was aged nineteen years old), but further attempts to arrange a home visit proved problematic because contact could not be made with Adult O's mum over the telephone, or appointments were cancelled. However, Adult O did continue to receive deliveries of her nutritional feeds.

8.41 On the 22 October 2020, the Dietician identified that there was an emerging theme of not being able to see Adult O at home and contacted the GP to determine if they had any concerns.

[27] https://sepsistrust.org/get-support/support/support-for-relatives/?gclid=EAIaIQobChMIlfX-mfj28wIVO4BQBh2LcAB9EAAYASAAEgK0s_D_BwE

[28] Referring to services based within hospital and community settings
[29] Private provider offering NHS community healthcare services
[30] An expert in diet and nutrition
[31] Private provider of nutritional solutions
[32] A tube directly placed into the stomach to provide nutritional support
[33] Nutrition (artificial feeding) through a tube

8.42 This is an example of good practice on behalf of the Dietician, however, when contact was made with the practice, a GP Administrator said that Adult O was last seen by the practice in September 2020, and no further action was taken. It has been reflected that this was a missed opportunity for agencies to seek safeguarding advice and for information to be shared relating to the emerging themes.

8.43 At the same time, the Dietician also contacted Nutricia and arranged a joint home visit for November 2020, but sadly, Adult O had passed away by then.

8.44 Adult O was in receipt of manual handling equipment which was provided by the Accessible Homes Team. The last involvement from an Occupational Therapist (OT) was in January 2017 when adaptions were made to the house and manual handling equipment provided.

8.45 The OT visited the property and felt confident that Adult O's mum demonstrated how to safely use the equipment. A further call was made to Adult O's mum in February 2017, and Adult O's mum reported that she was managing well with the equipment.

8.46 The Accessible Homes Team is not commissioned to provide a long-term case management or reviewing role, and therefore there was a reliance on Adult O's mum to contact them if she needed support. There is evidence within the records that after 2017 the team had tried to contact Adult O's mum via the telephone, but unfortunately there was no answer.

8.47 Adult O's mum explained that she would turn and transfer Adult O by manually lifting her rather than using the available equipment. This was an obvious risk of injury to Adult O, and her mum. This was despite there being evidence in records that Adult O's mum was given training and demonstrated successfully how to use the equipment in 2017.

8.48 Adult O was at high risk of developing tissue damage due to a variety of risk factors, including her physical disability, and the fact she had previous pressure sores. Pressure

sores are often preventable, in accordance with the NICE clinical guideline [CG179] for '*Pressure ulcers: prevention and management*,' (2014),[34]

8.49 The aforementioned NICE clinical guideline [CG179] advises that clinical input for those at high risk of pressure sores should include regular completion of an evidence based tissue viability risk assessment, such as the Waterlow score.[35] Also, it recommends careful care planning to include tailored information for the person and their carers regarding when a person should be repositioned, and what pressure relieving equipment they are assessed as requiring. Adult O's tissue viability needs were being monitored primarily by her GP, if she had been referred and known to the community learning disability services, this may have promoted better oversight of her tissue viability needs.

8.50 Throughout the SAR process it was identified that not all agencies were aware that Adult O's mum had anxieties regarding health appointments and environments. This is correlated with one of the identified root causes of there not being the expected multiagency working during Adult O's transition.

8.51 If a proper and thorough transition had taken place (in accordance with the NICE guidelines) this would have been a crucial time where this information could have been shared, discussed, and planned for, with a dedicated named worker who would have built a trusting relationship with Adult O and her mum.

8.52 Adult O should have also been offered the annual learning disability health checks (which she should have been offered from the age of fourteen), by her GP. Having these checks would have provided an opportunity for the GP to understand who was involved in Adult O's care. Potentially, the GP would have recognised that Adult O had minimal health and social care input, and referrals would have been made to the relevant agencies.

8.53 Annual learning disability health checks are devised to help the GP understand the persons health needs better, and the process is very important to ensure that the transition from children to adult services goes well. It would have also provided a

[34] https://www.nice.org.uk/guidance/cg179

[35] A risk assessment that gives estimated risk for the development of pressures sores

mechanism to check that Adult O's mum had all of the support she should have been getting.

8.54 The evidence suggests that agencies did not work effectively, and in an integrated way, as they should have done, agencies did not always respond to risks appropriately when they were highlighted. The lack of multiagency information sharing and working increased the risk of Adult O's health and social care needs not being met.

To identify what prevented action being taken when opportunities arose to safeguard Adult O.

8.55 The lack of a multiagency approach to support Adult O and her mum meant that important information (such as Adult O's mum's anxieties of health appointments), red flags (such as Adult O not attending health appointments) and potential risks (such as health needs not being met), were not shared across the system.

8.56 Agencies that came into contact with Adult O appeared to largely work in silo, meaning that they worked within their own organisation, and completed their own short piece of work, but did not share or obtain information from other agencies. There were frequent missed opportunities to seek safeguarding advice when there was continued evidence of Adult O missing health appointments.

8.57 When Adult O was admitted to hospital in October 2020, it was good practice that the hospital made a safeguarding alert to Adult Social Care because they were concerned about her physical condition.

8.58 However, Adult O's mum shared with the Author and Chair that because of this safeguarding concern she felt judged by the hospital staff. During the learning event, a representative from CHFT apologised for this unreservedly and stated this is not how Adult O's mum should have been left feeling. On reflection, more should and could have been done to explain to Adult O's mum why the alert was made, and what it meant.

8.59 When Adult O was a child there appears to have been better escalation of safeguarding concerns regarding missed health appointments and concerns that Adult O's needs were not being met. This is probably due to there being more services involved

connected to the school, better multiagency communication, and the fact the school inadvertently took on a case management role.

8.60 At the learning event it was discussed and reflected that in both child and adult services, all agencies involved did not have an effective 'was not brought' organisational policy, or they were still working under an organisational 'did not attend policy.'

8.61 A 'did not attend' policy is designed for when a patient does not attend an appointment, and more often than not this means they are discharged from the service after a series of non-attendance. However, a 'was not brought' policy has a safeguarding focus and relates to patients who rely on others to take them to an appointment.

8.62 The community agencies involved in Adult O's care did not have an equivalent policy that could have been exercised when Adult O could not be seen at home, and thus, could have provided Adult O with additional safeguards.

8.63 There needs to be clearer policies for community staff who are unable to access and see patients within their own homes. A 'did not see' (suggested name) policy should encourage professionals to see the situation from the 'person at risks' perspective, to include when to seek formal safeguarding advice, and the importance of multiagency communication.

8.64 There were missed opportunities for professionals to seek formal safeguarding advice when various concerns were being muted by individual agencies. On reflection, agencies agreed at the learning event that safeguarding advice should have been sought, and they should have considered making a safeguarding alert to social care under the category of 'neglect and acts of omission.'

8.65 The act of neglect and acts of omission can be intentional or unintentional and relates to when a person at risk is reliant on another person to provide care. Neglect and acts of omission can include ignoring a person's medical needs, failure to provide care and support and withholding the necessities of life, such as medication.

8.66 If formal safeguarding advice had been sought when professionals had concerns about Adult O being at risk, this may have progressed to a Section 42 enquiry.

8.67 All Local Authorities (social care) must make enquiries, or cause others to do so, if they believe an adult is experiencing or is at risk of experiencing abuse or neglect (Care Act 2014). If the Local Authority was made aware of the professionals' concerns this may have led to the enquiries that were required and may have highlighted that Adult O and her mum needed more support.

To examine to what extent the Mental Capacity Act (MCA, 2005) and best interest decisions were considered at key points for Adult O and her carers.

8.68 The MCA was published in 2005 and implemented in 2007, and as a piece of legislation it safeguards people from the age of sixteen. In Adult O's case there was no evidence of the MCA being used, embedded or considered in practice.

8.69 When Adult O turned sixteen this would have been a time for agencies to assess her mental capacity regarding important life decisions and future care. Adult O's mum would have had parental responsibility[36] for Adult O until the age of eighteen, but Adult O's ability to make decisions for herself from the age of sixteen should have been considered under the MCA and explained to Adult O's mum.

8.70 When Adult O turned eighteen, her mum no longer had parental responsibility nor did she have a formal legal authority in the way of being a Court Appointed Deputy[37] or Lasting Power of Attorney,[38] to make health and welfare decisions. It is reflected by agencies involved in this review that this can be a confusing time for parents and the legal duties and responsibilities need to be explained and parents need to be supported through the transitional changes themselves.

8.71 Notably in 2018, when Adult O's mum declined day services for Adult O, all practicable steps should have been taken to support Adult O to make this decision for herself, and to seek her views and wishes. A formal assessment of her mental capacity should have

[36] Legal duties a parent has for their child
[37] When a person is appointed by the Court of Protection as a deputy on behalf of someone who does not have mental capacity for specific decisions
[38] Legal documents where a person appoints one or more people (known as attorneys) to help make decisions in the event they do not have mental capacity in the future to make decisions themselves

been assessed by Adult Social Care, and a best interest decision made if she was deemed not to have been able to make that decision herself.

8.72 This is not to say that Adult O's mum would not be involved, it would have been equally as important for her to be consulted. However, there is no evidence in the records that consideration or support was given to Adult O so her voice could be heard when decisions were being made about her life.

8.73 If Adult O received a formal transition process from child to adult services there is more likelihood the MCA would have been considered. Issues relating to consent and capacity could have been thought through, and Adult O would have had the opportunity and support to voice her own thoughts and wishes.

8.74 There is no evidence that Adult O was considered by the agencies that she may have been deprived of her liberty and required a Court of Protection, Deprivation of Liberty (CoPDoL11) authorisation[39].

8.75 Whilst Adult O was cared for by her family and did not have a health or social care package of support, it would have been important to formally assess her capacity to make decisions about her care needs, and to consider if she met the criteria of the 'acid test' as set out in 'Cheshire West and Chester Council' [2014] UKSC 19 case law[40].

8.76 This meant that Adult O may have been objectively deprived of her liberty (in her best interests) and because Adult Social Care knew of these arrangements (although not funding any of the care and support), it became imputable to them within Article five of the European Convention on Human Rights (ECHR) and Re: R [2016] EWCOP33 case law[41].

8.77 Advanced care planning (including palliative care) was also important in the context of the MCA because Adult O's mental capacity should have been assessed and her views

[39] Application made to the Court of Protection to authorise where a person is being deprived of their liberty
[40] https://www.39essex.com/cop_cases/1-p-v-cheshire-west-and-chester-council-and-another-2-p-and-q-v-surrey-county-council/

[41] https://www.39essex.com/cop_cases/re-r/

and wishes obtained, in regard to her future care planning. This would have also incorporated the views of her family.

8.78 Whilst MCA is of main focus here, in Adult O's case there was a general lack of legal literacy in both child and adult services, where it was not engaged or considered.

8.79 Legal literacy is the term given to reflect the ability a professional has to engage and understand legal rules within their practice. These legal matters include legislation (such as the MCA), relevant case law in their area of expertise, a strong engagement with ethics and understanding of Human Rights. This does not require the professional to become legal experts, but they need a good foundation of legal literacy which will encompass the recognition of the legal basis from what their practicing.

9 Good Agency Practice

9.1 At the learning event it was identified as good practice that the Consultant Paediatrician made many attempts to engage professionals in the transition process in 2016 (when Adult O was aged eighteen years old).

9.2 Good multiagency working was evident when Adult O was at school and Adult O's mum seemed to have a better relationship with health and social care professionals at that time.

9.3 It has already been identified that there was good practice on behalf of the Locala Dietician in October 2020 when she identified that there was an emerging theme of not being able to see Adult O at home, and she had contacted the GP.

9.4 When Adult O was admitted to hospital in October 2020, a CHFT Learning Disability Matron visited her on the ward and made contact with several agencies to see who Adult O was known to. The Matron also referred to the Community Learning Disability Team because she realised that since leaving school Adult O had no contact with health professionals (aside from her GP).

10 Recommendations

10.1 KSAB to consider the key learning identified in this review and explore the development of any actions to address the learning. The key learning identified is;

- There was a lack of transition process for Adult O as she moved from being a young person, to an adult.
- There was a lack of accessible support and advice for Adult O's family regarding reasonable adjustments to promote access to health and social care services.
- There was no consistent agency response or approach when Adult O was not brought or was not seen by services.
- Communication and information sharing between agencies for Adult O was limited.
- The staff involved in working with Adult O had limited understanding of their legal responsibilities within their professional practice. Practitioners involved in Adult O's care required increased application and understanding of the statutory safeguarding responsibilities within 'Working Together to Safeguard Children' (2018) and The Care Act (2014) regarding 'Safeguarding Adults'. The legislative responsibilities that required increased application related to parental rights and responsibilities, and when this changes. Also, better application of the MCA (2005) and in particular assessing mental capacity and when to make best interest decisions. There needed to be increased understanding and awareness of the Deprivation of Liberty Safeguards (2007), and when a deprivation of liberty may be occurring in the community (as per the Cheshire West and Chester Council' [2014] UKSC 19 case law). The practitioners and services also required increased understanding and application of The Human Rights Act (ECHR, 1998), which is fundamental in providing rights based health and social care services.