



Swindon Safeguarding Partnership

Safeguarding Adult Review 'Summer'
August 2023

The reason for this SAR:

Following a health agency referral to the Swindon Safeguarding Partnership (SSP) Practice Review Group (PRG) (20/05/2022) prompted by the untimely death of Summer from Crohn's disease aged 19 years 9 months. There was a previous history of child safeguarding concerns in this case associated with treatment choices made by parents contrary to those advised by NHS clinicians treating the child. As Summer reached 16 years old she ceased to receive proactive medical treatment from the NHS for her Crohn's as the family opted for treatment outside the NHS. NHS clinicians were concerned Summer did not have the capacity to make the treatment decision and was following the wishes of her parents.

Summer's parents were contacted and asked whether they would like to contribute to the review, we did not receive a response from them.

A pen picture of Summer:

"Summer was a kind and confident young lady that cared very much about her friends and family. She cared about people which was evident through all her health and social care projects. She was very determined and was happy to state her opinions and have her voice be heard.

Summer enjoyed poems and one Christmas showed people how much she cared through making an Acrostic Poem for every staff member and student in the college.

She enjoyed socialising through planning games and would always challenge you to a game of Uno or top trumps.

Summer was extremely funny with an infectious laugh and giggle, having others laughing and smiling around her.

She had a great passion for music and contributed significantly to the college radio station. Summer had a great fact about music that she enjoyed sharing with others.

Summer enjoyed sweets and sour ones in particular, she used to say she had a sour sweets under her bed as a snack and sour skittles were her favourite she much preferred sweets to chocolate"

(The author is grateful for this pen picture of Summer by her tutor at college)

Time line of key events:

- Referred to CSC Disabled Children Team (DCT) 20/09/2017

- CSC investigation and outcome – closed 02/04/2020 and concluded Summer has capacity to make her own decisions and choices about medical care
- Transition planning commences from children to adult services three months prior to attending college returns to college after lockdown
- Date of death

This document:

This document forms the final output of this local SAR. It provides systems findings that have been identified through the process of conducting this SAR. These findings stem from key episodes within this case and that have implications for the current system in Swindon. They focus on settings, services and processes that seemed to be a key factor in this case but are also relevant to the system more widely and other professional networks not mentioned in this review.

Each system finding is first described. Then a short number of questions are posed to aid the SSP and partners in deciding appropriate responses.

Methodology: A Locally led SAR - What is it?

On this occasion the SSP decided to pilot a ‘new’ locally led SAR approach with the primary aim of utilising the local expertise knowledge and leadership of both the subject areas and how they work in the current system, with this in mind a small ‘panel of expertise’ was convened to work alongside the lead reviewer. This approach draws upon the Social Care Institute of Excellence (SCIE) Learning together model¹ in that it seeks to use this case of Summer as a ‘window on the local system’. It engages the local professionals earlier and at all stages and tries to understand how the case appeared to them at the time they were involved², to identify contributory factors that raise questions for the system generally in the form of ‘system findings’.

These findings stem from ‘key practice episodes’ that occurred within the case. These findings are used to pose questions for the current system in relation to how similar cases within the system are approached and importantly what

¹ While this review draws upon the SCIE model neither the lead reviewer nor members of the ‘expert panel’ have received any training or recent training on using this model e.g. the recently SCIE developed SAR’s in Rapid Time model.

² With this in mind the panel of experts and lead reviewer met with the group of professionals directly involved in the case initially to discuss the KLOE and key practice episodes and subsequently to sense check the draft report and to translate the findings into clear actions and outcomes.

actions are required to change the outcomes for other cases coming into the system. Appendix 1 outlines the methodology step by step.

A note on bias:

The SCIE approach to conducting a statutory review is premised on the fact that they are trusted and safe experiences that encourage honesty, transparency and sharing of information to obtain maximum benefit from them. Most professionals will accept there is always a potential for biases to play out when conducting reviews, 'hindsight bias' despite knowing of it can persuade us to accept a single or linear view of events or fixed assumptions and can lead to a 'blaming tone' to a review.

In this review bias has formed part of the process of determining the TOR of this review (and de facto any other review TOR design)³ relying wholly on written composite reports by each agency involved. In this case assumptions formulated the KLOEs to be tested out with the practitioner group and these assumptions proved a little inflexible at times by trying to fit the information into the prescribed view of the case. The important point here is the need to 'test out' and allow flexibility in the interpretation of events and what they suggest about the system currently.

Specifically in the case of Summer the starting position (determined by the TOR and the PRG discussion) was one of an adult who lacked capacity to make a treatment decision and was not seen as an adult in her own right where professionals were reliant upon the parental view in place of those expressed by Summer herself believing the parents to be coercive and controlling. The discussions with those closely involved in the case sheds a differing view of Summer in her last 2 years, her capacity and her ability to make her views and wishes known.

Parallel Processes:

LeDeR:

Any person who dies who has learning disabilities or who is autistic will be subject to a Learning Disabilities Mortality Review (LeDeR), where a decision to conduct a SAR is made the LeDeR review will be put on hold until completion of the SAR, the LeDeR review will occur in due course.

Coroner's Inquest:

³ This inherent bias raises important questions about how TOR are constructed without the benefit of the practice view at the time particularly if rigidly followed.

There was limited involvement by the Coroner and the Inquest was opened and closed immediately, as the Coroner was satisfied that the referring clinician completed the death certificate without the need for a post-mortem.

Focus of this review:

Summer was 19 years and 9 months when she died, she had complex medical needs and neurodiverse conditions influencing how she and her parents worked with professionals.

She had a longstanding Crohn's condition, a diagnosis of Autism and a learning disability. Concerns hinged on her choice of treatment for her Crohn's disease (Holistic - obtained from the United States of America) the influence of her parents on these decisions from childhood into adulthood, the lack of any treatment for Crohn's as an adult despite the risk of harm and death from no treatment. There was a lack of any repeated Mental Capacity Act (MCA) assessments as an adult on this treatment decision (Capacity for this was last assessed at 16 years) and lack of any health follow up. Given these factors the PRG identified the following eight KLOE's to explore through this review;

- Transitions process including following of NICE guidance – protocol in Adult Social Care and condition specific for LD and Autism
- Role of education – believed to be home schooled then returned to specialist provision and its impact on post-18 education
- Recognition of Autism and learning difficulties when working with Summer as an adult in her own right and offering of independent advocacy.
- Consideration of the need for completing capacity assessments with young adults with additional needs
- Relationship and interface between professionals and parents – was there potential influence of parents on making treatment decisions and how decisions were made for Summer as an adult?
- Impact of stepping outside of conventional medical treatment pathways including follow up appointments.
- Impact of ways of working as a result of the pandemic – lack of face-to-face appointments, missing signs of risk, staffing and psychology waiting list in CAMHS
- Safeguarding interventions when Summer was 16 years old

Feedback on the findings:

As part of the methodology of this review the professionals involved with Summer were invited to two sessions (session 1 - 9/2/23, session 2 – 10/5/23) the first to consider the KLOE in detail, the second to consider the draft findings presented in a first draft of this report in relation to the current system in place in Swindon.

In addition the 'panel of expertise' met 13/06/23 to agree the final report and its findings.

Looking beyond this case:

At the outset, this review has sought to find 'system findings and factors' that are illuminated by looking at the case. These findings are the underlying issues that helped or hindered in the case and are systemic rather than one-off issues. This requires that we think beyond case detail to what it suggests are the system issues as they present in the current system.

Systems findings:

Finding 1: There was a gap of a year where Summer was on roll at school but not attending education, this affected information sharing and transition planning.

Retrospectively as part of this review it took some investigating to work out what the official education placement status was at the time of Summer not being in education. It was believed she was being elective home educated (EHE) but not recorded as such as she was still on roll at the last school she attended. In reality she remained on roll between 01/09/2017 - 20/04/2020 with ongoing poor attendance. This had implications for both information sharing and transition planning.

There was a gap between Year 11 and attending college, Summer was never Electively Home Educated. The plan was for her to go to Sixth Form at school, but during that last year, she did not attend, and she withdrew from school due to a breakdown in the relationship with the parents. An EHCP Coordinator had responsibility for the EHCP review process with the school including inviting others working with Summer or who she was known to into the process.

While COVID was responsible for disruptions in education and between the school and Education Welfare Officer (a traded service in this case), the school would also have had an attendance plan for Summer but it's not clear how effective this was during the COVID period or before, School would have been following Government Guidance "[Schools COVID-19 operational Guidance](#)"⁴ for children and young people who were shielding during the pandemic. However, Summer's attendance was very poor prior to COVID.

When a referral was received by the Transitions Team (Summer aged 17 ½) key information regarding previous safeguarding concerns was not shared and therefore not considered in the triage of this referral. Had the information been available the outcome of the triage process would have been immediate planning for transition.

⁴ [\[Withdrawn\] Actions for schools during the coronavirus outbreak - GOV.UK \(www.gov.uk\)](#)

Usually, a child with complex needs who is open to Children's Social Care (CSC) would be referred to the transitions team at 14 years, where the case history is shared, CSC would ensure the transition team are communicated with and invited to all Child In Need reviews to understand the needs of the person and the plan in place which would then feed into the Care Act assessment. In this case CSC stepped down the case from Section 47 to Child In Need when Summer was 16 years and 10 months then closed 4 months later as Summer was opting out of Child In Need. Access to information on Summer has been restricted or locked due to Summer being deceased which has meant absolute clarity about information sharing and whether processes were being followed has not been possible.

At the meeting with the professional group as part of this review it was reported that the relationship at that time between the Disabled Children's Team and the Transitions Team was challenging and information was falling through the net, it was also at the start of COVID, which further exacerbated information sharing. Summer was closed to Disabled Children's Team there were no safeguarding concerns, and no historic concerns were shared. The professional group (as part of this review) talked about a pre-existing system 'Capita' where historical information held by children's services could be viewed by adult services at the point of commencing a Care Act assessment. Now the Transitions Team would need to be prompted by the referral information to identify any historical safeguarding concerns.

In working out this finding other questions arose not directly related to the specifics of the case but the system more generally relating to what monitoring systems are in place for children both in education and those Electively Home Educated or privately educated who have health care needs.

A child with and EHCP and who is Electively Home Educated will have annual reviews in the same way that a child does on roll at a school, the guidance around this states:

As with other children educated at home, local authorities do not have a right of entry to the family home to check that the provision being made by the parents for a child with special educational needs is appropriate, and may only enter the home at the invitation of the parents

Even if the parent is making suitable alternative arrangements by the provision of home education the local authority is still under an obligation to conduct an annual review of the EHC plan, and that should provide an opportunity for parents to seek additional support or discuss alternatives to home education. (ref⁵.)

⁵ Working together to improve school attendance Guidance for maintained schools, academies, independent schools, and local authorities May 2022.

However, this review has identified a lack of systems in place to identify children taken out of education who would meet the criteria for a EHCP and early transition planning due to their health care needs and conditions at the time of being taken out of education to ensure they are not lost from the system and their transition planning commences as directed by NICE guidelines.⁶

Questions for the Swindon Safeguarding Partnership

How can the SSP ensure that any child on an EHCP who continues to be on educational roll but not attending receives timely EHCP reviews?

In addition, how can the SSP ensure any child Electively Home Educated with an existing EHCP in place or conditions where this would be likely if remained in school are monitored to ensure transition planning still occurs for these children in a timely way and in accordance with NICE guidance?

What structures need to be put into place to give assurance all relevant safeguarding information is gathered from all agencies working with the child and family and shared with the transition team?

SBC have introduced a new 'Attendance Strategy' (Oct 2022) which relates to the revised 'Right Help at the Right Time Threshold Guidance', what assurances are in place to demonstrate both are working in conjunction with each other?

What other examples are there in the system, what audits could be done?

Transition from paediatric health to adult health

Finding 2: Current patient review management systems are not refined enough to consider vulnerability factors to be able to override the 'low priority' status meaning timely reviews are less likely and the risk that vulnerable patients may come to harm as not being seen.

Summer was transferred early from Paediatric care to adult care aged 17 and a half the paediatric and adult gastroenterology services did communicate (verbally and in writing) regarding Summer as a handover and appropriately. As part of this transition it is routine practice for the paediatrician to write to the GP and relevant specialists to hand the patient over.

The paediatric consultant transferred Summer's care to the adult team and she was seen face to face in clinic in Aug 2019 (17 year 3 months) this was her initial transition appointment. At that appointment parents and Summer would have

⁶ Ref. Transition from children's to adults' services for young people using health or social care services NICE guideline [NG43]Published: 24 February 2016

been given a phone number and e-mail address to contact the service for advice or to escalate deteriorating physical health. In this case there was also a verbal handover between speciality consultants.

Summer's next clinical review was by a telephone clinic in August 2020 under COVID restrictions⁷ where the discussion was mostly with her mother. The doctor was advised by Summer's mother that 'symptoms were well under control' with opening her bowels once a day. It was recorded that 'Summer's mother thinks this is the best she has been for many years and she has colour in her cheeks'. This information would have led clinicians to believe that Summer was physiologically reasonably well at this time she was also spoken with by the clinician at the time. This consultation concluded with a note to the GP to address her mental health and anxiety, a repeated faecal calprotectin test to be completed by parents and returned to the hospital and being kept under follow up by the gastroenterologist this is understood to be at six months. This last clinical review was during the early stages of the COVID pandemic where the clinician was wholly reliant on the reported progress given by the parent and the conversation with Summer.

The Trust would have been relying on the patient self-escalating physiological deterioration or reliant on escalation via GP/Primary care services or through the use of the IBD Specialist nurse phone line or e-mail system. In the hospital letter following the appointment August 2020 to the GP, copied to the IBD Nurse Specialists and the Consultant Paediatrician is the following paragraph:

This patient had a telephone consultation appointment and was not seen face to face due to the current outbreak of COVID-19. The patient could not be examined and therefore there is always a risk that things could be missed. However, it is felt by the Gastroenterology Department that the risks of missing pathology is far outweighed by the benefits of reducing the risk to the patient of COVID-19 by bringing them to the hospital. We will resume normal face to face consultations as soon as possible.

This was the last clinical review of her Crohn's by an NHS health professional. Summer's six month follow up appointment with gastroenterology never materialised as she was not on the conventional treatment that would have promoted a six month follow up from gastro specialist nurses therefore seen as 'low risk' and the case was managed under 'low risk' processes and would have required either the patient or GP on the patient's behalf to trigger a priority review.

The current processes are not refined enough to accommodate vulnerability indicators which prevents the ability to flag patients who may be in a 'non-booked appointments' list who may not be able to easily escalate their own concerns regarding their physiological status or who may rely on others to escalate on their

⁷ The service stance at the time was that 'the risk of missing pathology is far outweighed by the benefits of reducing the risk to the patient of COVID-19 by bringing them to the hospital'.

behalf. Escalation is via the GP/Primary Care system. This is acknowledged as a system risk by the acute Trust where a project has now started to target patients with a learning disability.

Questions for the Swindon Safeguarding Partnership

How can the approach to managing patient volume be improved to ensure all vulnerable indicators or factors are routinely considered before a patient's review is allocated a priority level?

Finding 3: Once in education and an EHCP in place, the college were not fully aware of the nature of Summer's complex health needs and what to be specifically alerted to.

Educational organisations often have their own healthcare staff purposefully in place to support pupils with their health needs. Sharing of sufficiently detailed health information to enable educational settings and their health staff to respond better to health care needs does not happen routinely.

In this case education only had a care plan in place regarding toileting needs and encouraging Summer to eat regularly and often and to report back to the parents. They were not aware of any medical treatments and appointments or any significant impact of Summer's health conditions to be aware of; or who to report to in health. They were also not aware of the previous safeguarding concerns that health had raised.

At the consultation point of allocating Summer educational provision the college received a draft EHCP, which lacked sufficient information, the college was aware of Crohn's but not in detail. By this point there had been a breakdown of schooling over a period of time, the college carried out a home visit in favour of a school visit to see Summer before being placed there. This visit included a representative from the transition team and Summer's mother to give an overview and to reengage with the family. This was at the start of 'lockdown' and Summer had only attended one day. During COVID the college did weekly check-ins to students, they called Summer twice a week and also hand delivered resources. On her return to college after lockdown, her attendance was 91%.

The college offered a high level of support to Summer, they extended the consultation process for accepting students and conducted a home visit to see Summer and had regular contact with her during COVID. The college Summer attended do have a medical team on site who could have been more involved had the relevant health information been communicated to the college e.g., the impact of Crohn's on Summer.

Questions for the Swindon Safeguarding Partnership

How can the Swindon Safeguarding Partnership improve the level of communication and information sharing between health and education to ensure education are fully briefed on the nature of the child's physical conditions and what to expect over time?

How robust are current Multi-disciplinary Team processes in place that support working the most complex cases where there are chronic health issues?

Finding 4: Health professionals were over reliant on the parents usually the mother for communication with Summer about her access to health treatments and reviews this rendered Summer invisible from view.

There was a tendency to not see Summer in own right especially within health services where the majority of the communication about Summer was through her parents, especially her mother.

In primary care, there was a specific instruction to only talk to the mother in relation to health concerns and treatments because Summer trusted her mother. The context of Summer's fear of healthcare settings relate to a traumatic experience whilst having bloods taken previously, she also had high levels of anxiety particularly health anxiety. Over time the family had a high level of mistrust towards the NHS particularly as they were opting out of NHS directed care in favour of holistic treatment from outside the UK. This mistrust extended to the doctors within primary care.

As part of this review, Primary Care recognise they could have done more to build a relationship with Summer, seeing her more face to face, challenging the parents making further adjustments to support her access to health independently. Part of this adjustment would be to make regular contact with the individual especially at times where there are no immediate acute health concerns.

Adult mental health only made contact virtually with Summer and all of them with mother present and Summer in the background.

Clearly, the health context added in a problematic factor in relation to working with Summer, she had a needle phobia, a fear of health settings due to her health anxiety and a long-standing mistrust of the clinicians none of which would have help to calm any interface with her. These were key factors that consistently got in the way of working with Summer as an individual.

This contrasts significantly to that by education who worked mostly with Summer (on her own) in the educational setting consequently they were able to ascertain her wishes, her feelings and respond directly to them along with

suggesting/agreeing adjustments to accommodate her needs both physical and how they would work with her educationally.

This raises questions regarding how far health services are able/willing to make reasonable adjustments for individuals with LD and other complexities to ensure they are considered as a patient in their own right.

Questions for the Swindon Safeguarding Partnership

Are there lessons health can learn from the approach deployed by education to improve how health can make adjustments to ensure access to health by the patient along with any carer is not compromised and not over relying on the carer?

Are the SSP assured that all its partners understand when the need to make reasonable adjustments arises in their work with individuals especially those who have complex needs including neurodiversity that they do so and that this legal requirement (under the Equality Act 2010) is monitored and quality assured?

How well does the ICB understand the implementation of the NICE guidance listed below and other available resources with reference to improving access to health care settings it commissions and especially those within primary care?

- NICE guideline [NG96] Published⁸: 11 April 2018
- NICE guideline [NG54] Published⁹: 14 September 2016
- NICE guideline [NG11] Published¹⁰: 29 May 2015 (especially Chapters 1.1 – 1.3.4. in relation to this case).

Finding 5: The impact of COVID was twofold in this case (i) the wholesale change from face-to-face contacts to those conducted virtually or by telephone meant individuals particularly those with complexities were not easily seen or reviewed by key services (ii) because of these complexities COVID arrangements allowed Summer and her family to choose to self-isolate during the pandemic period.

Without a doubt COVID had a profound impact on the nation's health generally and access to health, social support services and education but particularly so for those who because of their health conditions were advised to or chose to, self-isolate. In this case it exacerbated the tendency to not see Summer face to face or communicate with her directly.

⁸ Care and support of people growing older with learning disabilities

⁹ Mental health problems in people with learning disabilities: prevention, assessment and management

¹⁰ Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

Consequently, the first impact compromised the quality of health reviews when they did occur relying upon virtual or telephone communication in addition the knock-on effect of services reconfiguring to address the immediate needs of the pandemic impacted on the routine multidisciplinary team meetings and interfaces that would have occurred.

At the beginning of the pandemic virtual contacts or no contact at all became known as a safeguarding 'blind-spot' as professionals were only seeing part of the picture and over reliant on what was reported by the individual or their carers or the little they were able to see virtually. This second impact feeds into the first, while provision was made by schools and colleges to accommodate children and young people who were known to children's services this was not a mandatory expectation and many chose to remain at home and not be seen.

The disruptions caused by COVID ran throughout this case as detailed in the above findings, for shielded children Children's Social Care visited their homes and saw them through their windows. The college made regular contact with Summer and visited to hand deliver resources.

The full extent of the impact of COVID may never be known, however what emerged relatively quickly was the increase in anxiety and emotional health/mental health of young people/adults, and with it a higher demand for already stretched services. Young people were particularly impacted by; social isolation, feelings of anxiety, a loss of coping mechanisms, a loss of motivation and reported depressive symptoms. For Summer, these would have been compounded by her being Autistic and having a learning disability.

Questions for the Swindon Safeguarding Partnership

Should the Swindon Safeguarding Partnership undertake an audit on the children who were self-isolating during COVID and have not fully returned to education or have not been seen face to face by their key-worker or lead health professional if they have health needs and from such an audit determine if a further Equality Impact Assessment (EIA) is required?

While virtual contacts/assessments or reviews became the 'norm' as a response to the restrictions imposed by COVID, this way of working has now been established in the practice of many services. What assurances are in place that all staff who conduct virtual contacts with the people they work with are supported and resourced to identify safeguarding issues and act upon them?

Finding 6: Contested opinions on mental capacity assessments should have been raised through the appropriate channels to resolve these differences of opinion in the best interest of Summer.

In this case there was a significant mistrust of NHS health professionals by Summer's parents, they were not accepting of the medical views regarding the appropriate treatment pathways for Summer (seeking holistic treatment from outside the UK) they refused the involvement of the lead consultant for her care at the point where Children's Social Care were involved due to safeguarding concerns raised by health.

In this case the mental capacity of Summer to make her decision on treatment choice was contested by health professionals managing her care and treatment. Health were of the opinion that Summer lacked this capacity but were not permitted by the family to conduct a formal Mental Capacity Act (MCA) assessment even though the medical team had made plans to do so, but Summer did not attend this appointment. This opinion was unable to be tested formally through an official MCA assessment and led to mental capacity act assessment being completed by the Local Authority Disabled Children's Team (DCT) (6.8.19).

As a general rule an 'assessor' any 'assessor' under the MCA should have the skills and ability to communicate effectively with the person. If necessary, they should get professional help to communicate with the person. Capacity assessments regarding decisions about health treatments are usually done by an appropriately trained and experienced healthcare professional who is either:

- recommending the treatment or investigation or
- involved in carrying it out

In respect of the treatment for Crohn's disease this would be the medical team, and because of its complexity the health specialist coordinating the treatment.

The Social Workers involved with the family conducted the MCA assessment possibly because they had the best rapport with the family and the family were in agreement as opposed to health and considered to be the only option available given the families resistance to working with health and therefore done with the best of intentions in mind. On reflection it was not the best decision as the Social Worker may not be experienced in carrying out MCA assessments for health reasons, but it did keep the family working with the DCT.

Health and social care practitioners and/or other relevant professionals and experts must be involved when an assessment and/or decision has particularly significant consequences. For example, where;

- There are disagreements with the person, their family or others about their capacity to make a decision.
- The person's capacity may be challenged by someone.
- The decision is about life sustaining or other particularly significant medical treatment.

It is uncertain if anyone checked what websites Summer had accessed in her search for understanding the side effects, one is mentioned in the MCA assessment which lists the professionals who support the website. Some sites are more accurate and evidenced based than others. More evidence-based sites would not conclude that medication could “kill you in 9 months”.

There did not seem to be any preparation in terms of education prior to the MCA for Summer to make an informed decision using reliable information (clinically evidenced based information). To conduct an MCA assessment of this nature given Summer’s complexities, it would have required considerable planning, reliable information being shared, and knowledge of the condition being considered and of the consequences of the decision to be made.

Ideally this MCA assessment should have been completed by health or at least jointly with a health specialist, however health colleagues were consulted as part of the assessment.

The conclusion of the assessor is that Summer had the capacity to choose her treatment plan for her Crohn’s disease. The outcome of this assessment was shared with health and Summer was closed to the Disabled Children’s Team soon after.

Once the outcome of this MCA Assessment was shared with health, health sought legal advice and were advised on all the possible next steps to take which included; reassessing capacity (via an independent assessor if necessary) and continue to do so, undertake Best Interest Decision and finally apply to the Court of Protection (CoP) given there were conflicting opinions on Summer’s capacity. It would be for the health lead clinician seeking this legal advice to decide whether, or not to act upon it being advice only. It would also be their responsibility to instigate the next steps if they chose to follow this advice and without delay.

In the event the lead clinician did not pursue this any further, this legal advice was sought through the route of email and not recorded within the patient notes but a copy of the legal advice was sent to the adult lead clinician in November 2019 (after the initial handover and after the initial transition appointment in Aug 2019) but known before the follow-up tel contact in Aug 2020. In the legal response to the practitioner there was a strict instruction under ‘legal advice privilege’ that the legal advice should not be entered into the patient’s medical records or shared widely within or outside of the Trust. In following this instruction this advice became lost to clinical view at the time Summer was seen or communicated with about her care. It is entirely speculative, but had this advice been acted upon its possible that an application would have been made to the CoP, however it is not possible to say if the CoP process would have resulted in a positive outcome for Summer but it could have done. Due to the circumstances of the case the opportunity to use the CoP process was lost and so the theory cannot be tested.

Reflections by health staff (GWH) as part of this review:

Health staff involved with Summer accept they should have done more with regard to the MCA assessment, they were relying on the DCT to support the MCA assessment, it is also acknowledged the real challenges at play when there are disagreements between clinicians and those they are trying to treat. At the time the Court of Protection processes were not well understood by the clinicians involved, their adult counterparts may well have had more understanding but whilst the legal advice was sent by email to the adult clinical lead it was not seen and therefore not acted on. The legal privilege prevented the information being placed within the record, which was a significant barrier in sharing this information. Such important advice would have warranted a more robust hand over on this information alone such as a face-to-face meeting clinician to clinician. This has been addressed by the Hospital Trust through MCA training and their plan to provide written guidance on the Court of Protection for all staff.

Questions for the Swindon Safeguarding Partnership

How assured are the Swindon Safeguarding Partnership that all staff in its partner agencies that are likely to undertake an MCA assessment are fully equipped to apply it in practice?

How assured are the Swindon Safeguarding Partnership that the Court of Protection processes are sufficiently understood by professionals working with older children and adults to ensure where there are contested opinions about capacity that the appropriate legal framework is deployed to ensure a speedy resolution?

Finding 7: Staff should have applied professional curiosity and repeated the Mental Capacity assessment, given that Summer was refusing potentially life sustaining treatment.

Summer had refused the treatment that was proposed by medical practitioners, preferring an alternative non-pharmacological approach to treatment. A patient's right to the refusal of care and treatment is founded upon the basic ethical principle of autonomy. This principle states that every patient has the right to make informed decisions about their healthcare.

Whilst this principle should be upheld, when a person is declining serious medical or life sustaining treatment, it is essential that professionals are professionally curious and ensure that the person declining treatment is informed and has the mental capacity to make that decision.

From the age of 16 to Summer's death at age 19, there was only one Mental Capacity Assessment completed; this was completed at the age of 17. After this initial assessment, further Mental Capacity assessments were not completed,

because professionals assumed Summer to have the mental capacity to make decisions about this decision.

Even though Summer was refusing potentially life sustaining medical treatment, the Mental Capacity Assessment was not repeated. Principle 1 of The Mental Capacity Act stipulates that there should be assumption of capacity, however, when people are making decisions to refuse serious or life sustaining treatment, it is imperative that practitioners have properly assessed the patient's mental capacity to make that decision and that there is robust documentation of the assessment. Given that Summer was making the decision to decline potentially life sustaining treatment, it would have been pertinent to repeat / revisit the Mental Capacity Assessment, as matter of course. When a person is refusing treatment, assessment of capacity should be repeated and reviewed regularly, clearly documenting:

- What the specific treatment is that a person is refusing. The assessment of capacity should determine if they can consent to refusal of that treatment.
- Understanding: The assessor should clearly explain to the person what their medical situation is and the proposed treatment; documenting what information was provided to them and if they could / could not understand this.
- Retaining: The assessor should determine if the person can retain the information about their medical situation and the proposed treatment options. The assessor should document what information was given and if the patient could / could not retain it.
- Using or Weighing: The assessor must discuss the benefits and drawbacks of the treatment options and explain the consequences of not receiving the treatment. Once they have given this information, can the person explain why they would rather refuse the treatment and what is going to happen if they do not accept the treatment? The assessor should document the discussion to demonstrate that the person could / could not use or weigh the information.
- Communicate: Document whether the person could communicate the decision either verbally or by any other means.

The assessor should then consider if there is a mental impairment impacting on the person's decision-making ability (known as the causative nexus), this could be any disorder or disability of the mind or brain and includes mood disorders. In the case of Summer, the assessor should have established if her diagnosis of Autism was impacting on her decision-making ability.

Questions for the Swindon Safeguarding Partnership

How assured are the Swindon Safeguarding Partnership that staff will complete robust Mental Capacity Act Assessments when people over the age of 16 are declining serious medical treatment and that Mental Capacity Act Assessments are repeated when necessary?

Finding 8: Autism and physical health

Recognition of the link between Autism and physical health conditions was not fully considered by those involved with Summer.

As is often the case for those with Autism, the service and professional attention are skewed by a focus on the behavioural and cognitive aspects at the expense of paying attention to the physical needs in tandem. Autism is commonly associated with a range of physical and mental health conditions which appear with greater frequency compared with non-autistic populations resulting in higher morbidity and premature mortality.

It is of utmost importance to raise awareness among healthcare professionals and bridge the gap between physical health and the implication of Autism as a whole-body disorder. Leaving these physical conditions undiagnosed and untreated clearly results in health inequalities. They can also significantly decrease a person's quality of life potentially leading to morbidity and/or premature mortality.

Many early deaths are attributed to physical conditions, including seizures, sepsis, cancer as well as immune, respiratory and gastrointestinal conditions such as constipation, Crohn's, outside of other accidental factors.

Post-mortem studies have also revealed an association between Autism and the presence of often undiagnosed physical conditions or physical symptoms being mistakenly attributed to the core behavioural and neurological features of Autism.

In this case Summer's emotional and mental health, particularly her health anxiety and needle phobia were recognised and being addressed until she was 17 via CAMHS and until she was 19 ½ by adult mental health.

However, she didn't have any physical health reviews during the last three years of her life, she was last seen by a school nurse who monitored her weight in March 2019.

People with Autism report feeling anxious about attending healthcare settings with a tendency to avoid going. Summer was known to have health anxiety and needle phobia, which played into accommodating her wishes and that of her parents for her not to be seen in a clinical setting. Not seeing the physical health aspects of Autism as important as the behavioural and cognitive meant no

attempts were made to undertake assessments of her physical health or make adjustments to ensure this happened and in the least traumatic way.

Crohn's and Autism:

More long-term studies are needed to fully understand how Crohn's disease affects the overall health of people with Autism. Gastrointestinal problems can lead to anxiety, sensory issues, challenging behaviours, and sleep disturbance. For that reason, it's important for adults and children with Crohn's disease to work with specialists to treat symptoms and identify triggers when possible.

Questions for the Swindon Safeguarding Partnership

How will the Swindon Safeguarding Partnership ensure all staff are aware of the inextricable link between Autism and learning difficulties and the increased likelihood of physical health conditions?

What will the ICB do to improve the rate and frequency of physical health checks for individuals with either Autism or learning disabilities?

Coercion and Control:

Based on evidence in Part 2 returns to the PRG as part of this review coercion and control from parents were highlighted as a possible concern, documented from childhood and potentially impacted on her decision making around her medical treatment, their undue influence on Summer and how she was viewed by professionals as a result of this; including the lack of an assessment of her capacity as an adult to make such decisions (Findings 5&6).

In this case there were several examples of coercive control, the decision to not attend education and declining meetings with professionals, refusal by parents to work with health professionals and allow them to conduct a MCA assessment on the health treatment being offered. Summer not being communicated with directly. All this limited her support and caused further isolation including influence over her physical health.

In the context of domestic abuse where coercion and control are now recognised as an insidious form of domestic abuse. The insidious nature of this is key to understanding its long-term impact and that those being coerced or controlled are unlikely to recognise it.

Coercive and controlling behaviour can impact on decision making. Gilbraith (1983)¹¹ described coercive power as 'used to inflict unpleasant or painful consequences on a person acting on their own choices so that they "choose" to follow the preferences of the person inflicting harm rather than their own' (Ingram, 2016: 2). People experiencing coercive control live in fear of the consequences

¹¹ Gilbraith, J. (1983) *The Anatomy of Power*, Boston: Houghton-Mifflin

of going against the rules that the person perpetrating the abuse has set up for them to follow. The tactics used by perpetrators of coercive control include threats, intimidation, isolation, and control over aspects of everyday life, whereby the perpetrator may 'limit space for action' (Home Office, 2015: 4), including space to make independent decisions.

This is now recognised in the statutory guidance, as demonstrated in the guidance to police to ask 'questions about rules, decision making, norms and fear in the relationship, rather than just what happened' (ibid: s2.27) when looking into identifying the offence.

Identifying coercion and control is complex and even more so in the context of an individual reliant upon another for their care and support and where they are autistic and have a learning disability. Children/young people with disabilities will lose their autonomy and agency according to the level of needs and complexities they have, this means the views of the carers will be more prominent than those of the person being cared for because of this dependency. Abuse of children with disabilities is a known hidden factor and is both undetected and underreported.

It is difficult to come up with a finding purely related to coercion and control identified in the agency submissions and from the focussed discussions with the professionals involved, but this case does raise an important question for the SSP about its identification in the context of families where children have complex needs and reliant on others for their advocacy.

Questions for the Swindon Safeguarding Partnership

How well are staff equipped/supported or trained to identify coercion and control in the context of working with individuals with complex health or social care issues?

What is in place to help people with learning disabilities to recognise coercion and control in their lives and how they could seek help or raise with trusted others to prevent abuse?

Safeguarding Interventions:

The safeguarding concern regarding Summer was first raised by health professionals in September 2017 when Summer was 15 years old, as a response to; the parents withdrawing from NHS health treatment for Crohn's disease, Summer being Autistic and having learning difficulties, concerns about medical neglect as parents not taking on medical advice and where the risk of complications to her condition could lead to death. The outcome of the first strategy discussion was for a section 47 assessment followed by an Initial Child Protection Conference in the November. At a Review Child Protection

Conference in September 2018 the case was stepped down to Child In Need as the view was there was no evidence of parents restricting treatment.

The case was re-referred in June 2019 due to concerns about 'disguised compliance' and delays and lack of access to treatment. Another section 47 was agreed but changed to Child In Need on review of the case by Children's Social Care. The emphasis at this point was to obtain the views and understanding of Summer on her health condition and treatment.

In July 2019, Summer (aged 17) was visited at home to ascertain these views and a formal Mental Capacity Act assessment was completed by the Social Worker and the Assistant Team Manager. Summer was deemed to have capacity to make decisions about her healthcare. The case was held under Child In Need until Summer declined to engage with Child In Need planning and the case was closed to Children's Social Care following Summer's transition to adult health provision and education provision being in place.

The safeguarding concern centred on whether Summer had capacity to make her own decision or whether she was being unduly influenced by the views and wishes of her parents. Once a decision about her capacity had been made the safeguarding intervention ceased. Health accepted the Mental Capacity Act Assessment completed by Children's Social Care and neither challenged it nor attempted to repeat it over time. Findings 5 & 6 above have dealt with Mental Capacity Act aspects of this case.

In this case safeguarding hinged on the question of Summer's capacity to make a decision regarding health treatments and within it the freedom to consent to, or refuse treatment or admission to hospital as a general principle afforded any child on reaching the age of 16. However, Summer was Autistic and had learning disabilities and the decision to be made was for a life sustaining treatment, the focus on capacity overshadowed the nature of the harm health professionals were concerned about. In adult safeguarding under 'making safeguarding personal' principles an adult is able to make 'unwise decisions' based on their capacity to do so even if it will knowingly bring them harm.

While a child of 16 in law can be treated as an adult in relation to consent to refuse treatment, due consideration must be given to the nature of the harm or likelihood of harm occurring. In this case it is not that no treatment was sought but that the treatment decision was for 'holistic therapy' from outside the UK declining NHS 'best practice' and recommended treatment for her condition and the significant risks associated with this choice. With 'hindsight' it is easy to suggest what could have happened differently but legal involvement would probably have been helpful to determine what could be done within the existing legal frameworks and settle the differences between the agencies and the family.

Next steps:

Turning findings into outcomes

A table working out the types of outcomes we might hope for from addressing these findings within the current system has been produced. The table has been populated virtually by members of the 'panel of expertise' and will be commented on, monitored and progressed by the Swindon Safeguarding Partnership Practice Review Group. Working through these outcomes will require bespoke pieces of work that includes representation from system leaders, experts by experience and the relevant workforce and managers related to each outcome.

Acknowledgements:

The author would like to acknowledge the commitment and input from the 'panel of expertise' convened for this review and the honesty of the contributions of the practitioner group who attended practitioner sessions.

Appendix 1: Methodology for Review of ‘Summer’:

1. Scoping exercise –

- Produce TOR for review timeline etc.
- identify review panel members
- identify professionals group and their managers attendees

2. Small review team/panel consisting of subject experts in LD, MCA (ICB & LA,) Transitions between children and adult services, Lead reviewer will:

- Produce a set of focussed Qs from information within part 1&2 executive report and TOR following scoping to take to a practitioner session.
- Including what to ask the family- if we decide to involve them

3. First practitioner session held to use focused Qs to illuminate and explore barriers and enablers to good practice, untangling systemic risks, and progressing improvement activities,

- What was it like at the time?
- What is it like now?
- What needs to change?

4. LR and review panel write and agree draft report (mostly LR + BSU support+ review panel) and findings by adopting a ‘Rapid Review’ or process and template to achieve brevity – this will be taken to a 2nd professionals group to:

- agree findings and possible recommendations
- check TOR areas have all been covered
- identify any further areas to explore in depth

5. 2nd professionals group to sense check initial findings and further explore the factors and issues raised from PRG1 and highlighted in the RR report – work out what system/service/organisational changes are needed. This group may also need to include commissioners/strategic leads

- Translate findings into actions using - ‘logic model’ approach

Requires a description of how and why a desired change is expected to happen

Links activities to outcomes, articulating the mechanisms that will lead to change

