Bristol Safeguarding Adults Board

Safeguarding Adult Review

Christopher (6th June 1984 – 22nd December 2015)

Professor Michael Preston-Shoot

March 2018

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1. Introduction

1.1. Christopher died in Bristol Royal Infirmary on 22nd December 2015. The Coroner's "Certificate of the Fact of Death" dated 6th January 2016 records the cause of death as respiratory tract infection, short bowel syndrome[1] and previous surgery for enterocolitis[2]. A Death Certificate, dated 31st May 2016, issued following the conclusion of an Inquest, records the same three causes of death but adds that Christopher died from natural causes contributed to by his recent weight loss, the fact that he was an in-patient with poor mobility, a poor cough reflex and recent general anaesthetic.

1.2. A formal record of the inquest concludes that Christopher died as a result of a number of chronic underlying health conditions which included cerebral palsy, learning difficulties, epilepsy and short bowel syndrome. These were conditions that Christopher had had since birth and which had been managed throughout his life. Between September 2015 and his admission to Bristol Royal Infirmary on 4th December 2015, the inquest record states that Christopher had lost a significant amount of weight and was exhibiting challenging behaviour which included times when he was not eating and drinking. Following his hospital admission he continued not to eat and drink adequately, resulting in him being fed through a nasogastric tube from 13th December 2015. On 22nd December 2015 he suffered a cardiac arrest and died. His death is recorded here as due to a respiratory tract infection, the cause of which was multifactorial.

1.3. The Coroner did not issue any Regulation 28 notices[3].

2. Rationale for carrying out a Safeguarding Adult Review

2.1. On 7th April 2017 Christopher's Father submitted a request to Bristol Safeguarding Adults Board for a Safeguarding Adult Review. On behalf of the family Christopher's Father states their belief that there were systemic failures by staff and agencies, with Christopher allowed to neglect himself by not eating, drinking or taking his medication, despite not having the capacity to understand the risks and consequences. The submitted request suggests that the agencies involved with Christopher neglected him and failed in their duty of care through inaction or the lack of a coordinated response. The family believe that there were missed opportunities to prevent his death.

2.2. The Bristol Safeguarding Adults Board has a statutory duty[4] to arrange a Safeguarding Adults Review (SAR) where:

[1] This is a malabsorption disorder caused by the lack of a functional small intestine. Most cases are due to the surgical removal of a large portion of the small intestine. Dehydration, malnutrition, obstruction, weight loss and serious infection can result.
[2] Inflammation of the digestive tract involving the small intestine and the colon.
[3] Under the Coroners and Justice Act 2009, schedule 5 (7), the Coroner is under a duty to make reports to individuals or organisations where this is believed to be necessary to prevent future deaths. Detail of the process to be followed is under Regulation 28, Coroners (Investigations) Regulations 2013.
[4] Sections 44(1)-(3), Care Act 2014

- An adult with care and support needs has died and the SAB knows or suspects that the death resulted from abuse or neglect, or an adult is still alive and the SAB knows or suspects that they have experienced serious abuse or neglect, and
- There is reasonable cause for concern about how the Board, its members or others worked together to safeguard the adult.

2.3. Board members must co-operate in and contribute to the review with a view to identifying the lessons to be learnt and applying those lessons in the future[5]. The purpose is not to allocate blame or responsibility, but to identify ways of improving how agencies work, singly and together, to help and protect adults with care and support needs who are at risk of abuse and neglect, including self-neglect, and are unable to protect themselves.

2.4. The Independent Chair of Bristol Safeguarding Adults Board agreed that the criteria for a Safeguarding Adult Review were met on 27th April 2017 on the grounds that malnourishment may have been a contributory factor to Christopher's death, with possible neglect due to misunderstanding of his capacity to manage feeding tasks. I was confirmed as the lead reviewer on 9th June 2017.

2.5. The membership of the SAR Panel comprised the members of the Board's SAR sub-group, with the addition of co-opted members representing at senior level the agencies which had commissioned or provided services to Christopher.

- Independent lead reviewer, overview report writer, and panel chair:
  - Michael Preston-Shoot
- Bristol SAB Business Manager
- Bristol SAB SAR Sub-group Chairperson
- Bristol City Council:
  - Care and Support Adults
  - Commissioning
- Bristol Clinical Commissioning Group
- University Hospital Bristol
- Bristol Community Health
- Freeways

The SAR Panel received administrative support from the Bristol Safeguarding Adults Board Project Officer.

3. Review Process

3.1.Scope and focus of the SAR [Terms of reference]

3.1.1. The key question to be addressed by the review was identified as follows: "what can agencies learn from this case about the effectiveness of care and support of adults with learning disabilities and complex health needs in supported independent living when they lack capacity?" From this initial question, several additional questions were deemed to be in scope, namely:

[5] Section 44(5), Care Act 2014

- How effectively was Mental Capacity Act 2005 legislation applied? What impact did mental capacity assessments have on core care tasks, such as nutrition and medication provision?
- How suitable was the process of assessment, commissioning and matching of care providers, including contingency plans?
- How was information about strategies of care and/or behaviour management shared between care providers during transitions between settings and services?
- How effectively was the interplay between Christopher's different health needs and disabilities understood and managed?
- How effectively was Christopher's family engaged with his care and support plan, and with the management of his health needs?
- How effectively was Christopher's voice and views heard and included?
- Was there parity of esteem in the receipt of care and support for an adult with learning disabilities and complex physical health needs?

3.2.Methodology

3.2.1. A hybrid methodology for a proportional, fully inclusive and focused review was agreed. The time period to be reviewed began with assessment for Christopher to move to supported independent living, which was accomplished in October 2014, and concluded with his death in hospital in late December 2015. The following agencies submitted individual chronologies of their involvement with Christopher:

- Avon and Wiltshire Mental Health Care NHS Trust
- Bristol City Council
- Bristol CCG
- Bristol Community Health
- The supported living provider
- University Hospitals Bristol Foundation Trust

3.2.2. When combined the chronologies highlighted the relevance of three particular time episodes, namely the transition from Christopher living at home to supported independent living, including the early months with The supported living provider; the period of significant deterioration in his health and wellbeing between August and December 2015, and his final period of hospitalisation in December 2015. The events and practice within these time episodes have been explored, drawing on observations from the transcript of the inquest and the perspective of family members.

3.2.3. From the combined chronologies and documentation already provided by the family and agencies involved, a number of questions were identified that related to events in one or more of the three highlighted time periods. These questions formed the basis of reflective conversations that were held with key professionals who had been involved with Christopher, facilitated and recorded by review panel members.

3.2.4. A half-day learning event was held at which issues, concerns and questions arising from the reflective conversations, combined chronology and other available information, including the transcript of the inquest, were discussed.

3.2.5. Specialist input has been available to the lead reviewer and the review panel from a specialist medical practitioner in order to clarify questions relating to Christopher's complex health needs.

3.2.6. Whilst all the agencies have cooperated fully with the review, some practitioners who were involved with Christopher during the relevant time period have either retired or left the agencies that employed them at the time. This has to some degree limited the available information on which this review has been able to draw.

3.3.Family involvement in the review

3.3.1. Family members met with the Chair of the SAR sub-group and the SAB Business Manager to discuss the review process. Family members were also consulted about and commented on the terms of reference.

3.3.2. Family members made available to the lead reviewer documentation pertaining to Christopher's life journey, placement in supported independent living, contact with medical and health care professionals, and the final period in hospital leading up to his death. They also made available documentation relating to the inquest into Christopher's death.

3.3.3. The lead reviewer met and/or discussed the review by telephone with family members to gather information and invite their comments on how agencies worked with them and Christopher.

3.3.4. Family members provided the pen portrait of Christopher which is included in the SAR. It is their wish that his given first name be used for this review.

3.3.5. Family members have been clear that, in referring Christopher's case for review, they hope that agencies will identify and implement lessons to be learned in order to improve practice for adults with learning disabilities and complex health needs.

4. Case Summary

4.1.Pen picture of Christopher from the family

4.1.1. Christopher was a remarkable young man given the difficulties of his birth. That he learned to live with the resulting complex and multiple disabilities which resulted, for so long, was also remarkable.

4.1.2. He was born at 26 weeks, weighing just 820 grams and no one had any idea what his life expectancy would be. He had numerous operations to correct hydrocephalus[6] and bowel problems, which left him with stunted growth and a unique set of learning and physical disabilities which would remain with him throughout his life. His understanding was limited, though he had a very good memory. His language development was slow but he eventually began to hold conversations, which though limited in nature could be entertaining, if not always pertinent to what was being talked about. He loved going shopping in Asda and was sociable

[6] Excessive accumulation of fluid in the brain.

and easy to manage when things were going well and his health was good. Because of his bowel issues, eating a meal could be a lengthy process and those around him needed to ensure that he had sufficient to eat to keep his weight stable and enough nutrients to keep him healthy.

4.1.3. When things were not going well he could lose weight quickly and withdraw his cooperation from those around him, turning inward on himself. Thankfully this did not happen too frequently. He was never really able to make any complicated decisions about his own life and often needed guidance, which had to be put very simply and in a straightforward manner. He remained unable to use money, read or follow any complex conversations or entertainment. He would however listen to music, which he enjoyed, and films such as Postman Pat or Mr Bean. He needed others around him to be positive and upbeat and his understanding of cause and effect was very rudimentary.

4.1.4. His mobility was never good and though he crawled as a youngster and eventually walked he needed help and used both a walker and a wheelchair for much of his life. His life was restricted in many ways but he also accomplished a lot, including going on holidays, and flying to America to see his mum. He loved visiting his friends and his cousins both in this country and abroad.

4.1.5. He had a great understanding within his own world and of those who he referred to as friends and whom he gave nicknames to. He would joke and laugh with those who entered his world. He had little understanding of the world of others or the wider world and did not really understand the feelings or responsibilities of others or show empathy. It was much easier to get alongside his feeling and emotions and in that way it was possible to give comfort or cheer him up if he was feeling low. Generally he was good fun to be with and showed a great sense of humour, enjoying life and his place in it.

4.2.Background

4.2.1. Christopher was born three months prematurely and had a brain haemorrhage shortly after his birth. As a result of his disabilities, which included cerebral palsy, epilepsy and learning difficulties, he spent his first five months in hospital. Before he came home he required major surgery for necrotising enterocolitis[7] and subsequent surgery to re-join his bowel. He was diagnosed with short bowel syndrome and bacterial overgrowth. Some years later he was diagnosed with autistic spectrum disorder and vitamin B12 deficiency.

4.2.2. He attended schools until the age of 19. He lived at home full-time from 2000. He is described by his Father as being happy during that time, attending college part-time and day centre activities.

4.2.3. A June 2002 social care assessment records that he was not eating and drinking properly when at a residential school in the late 1990s when he was not happy there. He has a history of boarding school and respite care. Respite care ceased when Christopher was at boarding school as a weekday border four nights per week but in fact he was at home more than away. It recommenced when he left boarding school in 2000. The 2002 assessment comments that

[7] A serious illness in which tissues in the intestine become inflamed and begin to die. Without correction perforation can develop that allows the contents of the intestine to leak into the abdomen.

respite care took a great deal of time and effort for Christopher to adjust to. He is noted in the assessment document as sensitive to changes in routine, which require careful planning. Family members agree that Christopher was sensitive to changes in routine but have commented that these did not require "careful planning." Without adequate food and fluid intake he would dehydrate very quickly. His Father had to be informed quickly if there were problems here.

4.2.4. He was diagnosed in 2006 with Crohn's disease[8].

4.2.5. His Father was appointed his Appointee for social security benefits.

4.2.6. A letter from a Consultant Colorectal Surgeon dated 13th May 2010 records that Christopher will need to be admitted if there are problems with bloating, abdominal discomfort, distension or pain and vomiting. Due to short bowel with probable burnt out Crohn's stricture this can cause symptoms of obstruction. The advice is conservative management at the time rather than surgical intervention due to risks of the latter for Christopher. This plan is determined by the Consultant with Christopher's Father as an outcome from a case conference, presumably a best interest decision. Long-term follow up for Crohn's is to be put in place and an early warning system should he be readmitted. The respite care service is tied into this arrangement, as were those treating his epilepsy. The supported living provider was made aware of this advice and plan when Christopher's Father gave them a copy of the letter.

4.2.7. A September 2011 social care assessment records that he is now receiving respite care and attending a Resource and Activity Centre. He remains very dependent still on his Father. He does not always like going to respite care and this has led to refusals to eat and drink – a protest, with feelings of abandonment. There is an early discussion of more independent living. When Christopher is anxious, this can lead to refusals to eat and drink. If he is faced with too many options he may get confused. Possible mental health concerns are noted. He is able to have choice in some areas of his life but for more important decisions he benefits from support. He cannot undertake daily routines independently.

4.2.8. An August 2013 social care assessment records that Christopher needs 1-1 support at mealtimes. He sometimes refuses to do physiotherapy exercises. His dietary routine is of paramount importance as this impacts on his health, mood and willingness to cooperate. The assessment notes Crohn's and vitamin B12 deficiency[9] but also hydrocephalus with a cranial shunt replaced in 2011. He is said to have very little sight. Anxiety affects his health and he may refuse to eat and drink. He sometimes worries about his Father. He can be affected by stress and the moods of other people and finds it difficult to be around people who are loud or shout. He cannot cope with too much choice as becomes confused. He needs support with decision-making. He is at risk of personal neglect regarding dietary and health needs. He may stop eating or drinking when feeling low – such changes need to be acted on quickly. He finds it hard to communicate emotional issues. Family members believe that this is the crux of Christopher's mental capacity, namely that he was unable to make informed decisions about his health or social care needs.

[8] An inflammatory bowel disease, symptoms of which include abdominal pain and weight loss.
[9] Anaemia that can make the individual feel weak and tired, being managed through quarterly B12 injections.

4.2.9. In 2013 his Father required major surgery followed by a period of recuperation and this prompted renewed consideration of Christopher's future living arrangements.

4.3.Narrative

4.3.1. What follows here, drawn from the combined chronology, inquest transcript, interviews with practitioners, learning event and discussions with Christopher's family, is a summary of significant events within the agreed timeframe. These events are organised around three time periods, namely from his placement in October 2014 to July 2015, from August 2015 to his hospital admission in early December 2015, and finally his time in hospital until his death.

4.3.2. Christopher moved into his supported living placement on 10th October 2014. Detailed planning for the move had begun in late July 2014 although the family had been preparing Christopher for a move for around one year. Although his Father had suggested that enhanced care would be appropriate, and indeed one residential setting had been visited early on by the family as part of their preparations, assessment concluded that independent living was the more suitable option and placement with the supported living provider was recommended. No other placement options were offered to the family. Staff involved in finding a placement believe that Christopher's Father inclined towards supported living as better suited to enabling Christopher to continue with his preferred activities, supported by the welfare benefits he received. Placement in supported living was also in line with Bristol City Council's accommodation strategy. Christopher moved in following one taster weekend. There were no other introductory events although Christopher had previously attended a weekend service run by the supported living provider and it was this contact, coupled with Christopher knowing another resident quite well, that encouraged everyone involved at the time that this location might be an appropriate setting. Those working with Christopher at that time believe that the pace of the transition was determined by the family but the family dispute that.

4.3.3. Christopher and his family were enthusiastic about his move and he settled in well. Although there were occasional challenges in getting him to attend his day service, and occasional refusal of fluids and verbal abuse, he appears to have managed the transition well. In November 2014 Christopher expressed reluctance to attend the day service. Family members believe that this was because of changes that had taken place in the type of service being offered and in the clients who attended the centre. An agreement is reached about how to manage this.

4.3.4. In December 2014 the GP refers Christopher to Bristol North CLDT, expressing a view that Christopher is finding adjustment to his new living situation tricky. It is suggested that he could be experiencing a depressive episode. An assessment finds no evidence of mental illness. A change in day service provider is negotiated in February 2015 and implemented in March because of Christopher's non-engagement. Despite occasional concerns about his health, with consultations between the supported living provider, GP and medical consultants, assessments and reviews conclude that he is clinically stable and compliant with medications and diet. Family members were not always made aware of these consultations. He has regular family contact which is positive.

4.3.5. Between July and September 2015 there are discussions about his diet, specifically the balance between supplement drinks and cooked food. In July 2015 a gastroenterology review concludes that the GP should try to wean Christopher off dependence on oral nutritional supplements and encourage consumption of cooked foods, believing a varied diet would be beneficial in the long-term. Christopher's weight is recorded as being 45.6kg[10]. The review was conducted by a locum who had not met Christopher before, whose notes record the move to supported living as a big change for Christopher and his Father. In the notes it is recorded that Christopher has taken to consuming Ensure, Polycal and Fresubin and was not really eating much cooked food. The doctor has recorded that he asked why Christopher was not eating and that Christopher may have said that it was because he was consuming so many of the supplement drinks[11]. The doctor concluded that some of the lack of eating was behavioural, related to the supplements and possibly also related to change in living circumstances. The medical record states that the doctor agreed with Christopher's Father's suggestion to try to wean his consumption off calorie supplements, aiming to replace with cooked food. A formal dietetic review is discussed but the medical notes state that Christopher's Father did not feel this would be particularly helpful at the moment and that it could be considered in the future.

4.3.6. Family members believe that the conclusions reached misrepresented what Christopher's Father had said at the review meeting. Christopher's Father has stated that throughout his life Christopher had eaten solid foods alongside oral supplements and had never refused medications at home.

4.3.7. There is one hospital admission in August 2015 for tests associated with problems arising from his short bowel. He is assessed as not having the mental capacity to make decisions about his care. In September 2015 a neurology review concludes that there are no concerns as Christopher is seizure free on current medication. He is discharged, the GP to re-refer if necessary. Family members do not believe that they were informed of this appointment or of the discharge. Also in September 2015 a coloproctology review records that Christopher is eating well with weight gain (45.9kg on 14th September, recorded as representing an 8kg gain in the last two years[12]). The advice given in July about weaning Christopher off calorie drinks and eating "normal" food is confirmed. On 16th September 2015 a placement review is completed. Christopher is recorded as doing well in the day service. A referral to a dietician is agreed in mid-September and made in early October 2015 as the supported living provider are concerned about his diet. Practitioners at the learning event were clear that they had routinely sought advice about how to respond to Christopher's desire to eat solid food.

4.3.8. Having previously been eating well, including solid food at home and since his move into supported living, and being compliant with his medication, he begins to eat little, to demonstrate challenging behaviour and to refuse medications, drinks and/or food.

[10] The medical notes record Christopher's weight at the following dates as: 36kg (11th March 2013), 44.2 kg (24th June 2014), 44.4kg (6th August 2014).

[11] This is one example where Christopher's relatives have noted how important it was to frame questions to Christopher carefully – see section 6.3.2.

[12] Family members believe that this misrepresents his weight which had been fairly constant for at least four years. The accuracy of weight measurements was questioned and required clarification during the inquest.

Christopher's Father is of the view that some of these reported challenging behaviours were misrepresented and exaggerated, as described in his statement to the inquest. There are other times during September and October when the supported living provider reports to Bristol City Council Social Intervention Team that things are generally positive.

4.3.9. The episodes of Christopher refusing medication, food and/or drinks escalate from late October. Between 2nd November and 4th December 2015, a total of 32 days, he refuses medications, food and/or drinks on 74 occasions. He loses weight and there are increasing incidents of incontinence. A referral to BIRT is made citing his low mood, refusal or delayed acceptance of medication, supplements and some meals, and challenging behaviour. GP records note that the supported living provider staff have suggested to Bristol City Council Social Intervention Team that Christopher be moved to another house better able to cope with challenging behaviour. Christopher's Father was not told about this suggestion at the time it was raised or subsequently at a meeting in the family home the day before his final admission to hospital, the purpose of which was how to better support the placement. This suggestion also appears in the Bristol City Council Social Intervention Team records, with Christopher reported as choosing not attend the day service, to be verbally and physically aggressive towards staff, refusing medication and choosing not to have personal care each day.

4.3.10. On 17th November 2015 the supported living provider reports a seizure to BIRT and the GP surgery. A planned admission by the GP at the same time is cancelled because Christopher begins to accept food and drinks. At the inquest the GP stated that she had not been told of this seizure and that had she known she would not have cancelled the planned admission on 18th November for rehydration. The family's view, explored at some length during the inquest, is that Christopher took his food and medicine on the basis that he would be stronger for his hospital admission and that he felt very disappointed when it was cancelled. A safeguarding referral is also made by the supported living provider on 17th November but is screened out because Christopher is being seen regularly by his GP, CLDT and BIRT. He is assessed by a Psychiatrist as not having the mental capacity to consent to medications, which should be given in his best interests, and there is an on-going informal assessment by BIRT staff with respect to his mental capacity regarding nutritional and hydration intake. The risk assessment records risk to self as moderate due to spells of not eating and drinking. Christopher is described as fixated on admission to hospital and it is suggested that he is exercising some control by his refusing to take medication. He is assessed as presenting as mildly anxious and angry, with low mood and a possible depressive episode. Anti-depressant medication is to be trialled, with a review in one month. Christopher's Father is told that this medication is administered and indeed family members thought that this was the cause of Christopher appearing "spaced out" on a subsequent home stay. However, it emerged at the inquest that Christopher had not taken this medication prior to his weekend stay at home and may not have taken this medication once back at the supported living provider alongside refusing other medications.

4.3.11. A professionals meeting is held on 23rd November although not everyone involved with Christopher's care is present. Christopher's Father was not invited to the meeting, as is usual practice with professionals meetings. However, he has stated that he was not informed that it was taking place. It also appears from the record of the inquest that an email that Christopher's Father sent that day, regarding his concerns that the dietary regime was not working, was not

discussed at the meeting. The meeting agreed on another referral to a dietician and the supported living provider discussing with Christopher's family the approach to be taken with respect to his diet and independent living. This discussion does not take place before Christopher's admission to hospital in December 2015. The dietician does not see Christopher before his admission to hospital on 4th December with weight loss and dehydration. Christopher's Father speaks to the GP, concerned about the effect of the anti-depressants and also Christopher's weight loss. BIRT and Bristol City Council practitioners meet with Christopher's Father prior to the December admission to discuss the approach to his health care needs.

4.3.12. The supported living provider updates BIRT, GP and Bristol City Council Social Intervention Team with their concerns during November and early December. Increasingly the supported living provider report concerns about the relationship with Christopher's family. Towards the end of November the GP requests an urgent gastroenterology review due to weight loss (at least 5kg), advice about management of his nutritional intake, and confusion between care staff and Christopher's Father over the regime of supplements and normal foods, causing potential detriment to Christopher's wellbeing. The GP and a specialist Learning Disability Nurse discuss the case and conclude that Christopher is attempting to exercise some control over his life by refusing to eat, take medications or drink. He has apparently told the Nurse that he does not like where he is living but he is also recorded as stating the opposite; similarly in conversation with the supported living provider staff with respect to contact with members of his family. They agree that these issues of control should be discussed with his Father but family members have stated that this was not done. A behaviour modification approach is planned by the Learning Disability Nurse. Appointments with the Dietician and Gastroenterologist are apparently scheduled to take place in the "next month or two."

4.3.13. Very soon after his hospital admission Christopher was assessed as not having mental capacity to make decisions regarding his medication and his nutritional and hydration intake. Initial attempts to persuade Christopher to accept his medications and to take food and drinks meet with little success. Fluid intake is the immediate concern, with plans for rehydration. His weight is recorded as 35kg. He is seriously underweight. A mental health review is escalated and he is seen by an on-call Liaison Psychiatrist with his Father. He is noted as having capacity to make some decisions, for example about choice of food. His Father is noted as saying that Christopher has been offered choices for decisions that he does not understand. The family believe that he was left a menu card for each meal time to make his food choices and food and medication were then left on his table untouched for hours. Hospital records do not contain any information about concerns having been raised at the time[13]. Drug charts record many occasions on which drugs were refused. Fluid/food charts record many occasions when food was declined.

[13] Leaving medication at the patient's bedside would not be in line with the Trust's Medicines Policy but according to the family happened.

4.3.14. During the hospital admission the supported living provider express concern about Christopher returning to his current placement. This concern was not shared with the family. A professionals meeting is held to discuss a potential new placement towards the end of this admission. The family were not informed of this meeting.

4.3.15. Christopher is recorded as saying he is scared of having a cannula and medication but could not explain this further. Sometimes to his family he appeared frightened. At other times he was brighter. Hospital records note Christopher's Father as saying that previously his son had accepted cannulas but, for some unknown reason, this admission felt different. Options are discussed with his Father and other family members, with the family actively seeking a more proactive intervention. Family members express concern at the delays in implementing a sequence of decisions designed to tackle his nutritional and hydration intake. A best interest meeting is held, with family members present, at which options and their associated risks are discussed and a plan agreed, including if necessary a general anaesthetic to insert a PICC line and to commence naso-gastric feeding. Hospital records note agreement on pursuing the least restrictive approach in line with clinical need and Christopher's condition, given the risks and distress associated with restraint and sedation. Six days after his admission, one of several attempted cannulation is unsuccessful so the plan for sedation to effect this is agreed with his family. On-going attempts to insert a cannula without the need for a general anaesthetic are unsuccessful with the result that a PICC line and naso-gastric tube are inserted by means of general anaesthetic.

4.3.16. Naso-gastric feeding begins, with advice from the dietician. Sometimes Christopher is bright and taking food orally; sometimes he is flat and declines food and drinks. An infection is treated with antibiotics. He complains of pain in his abdomen and tests are arranged. The hospital chronology documents that on the 12th December a medical consultant discussed with the family "do not attempt CPR" as part of developing a treatment escalation personalised plan for Christopher. Christopher's Father recalls that the consultant explained that resuscitation on the ward would be risky and could result in further brain damage, but that in theatre this was more straightforward. Both the family and the chronology supplied by the hospital are clear that, after reflection and discussion, the family agreed on DNR on the ward based on the information from the consultant, informing nursing staff. Christopher's parents understood that this decision would feature in the ward notes. The chronology from the hospital further records on 13th December that the documentation was not yet completed. There was no further discussion of DNR. The documentation was still not completed by the day he died, on 22nd December. Christopher subsequently experiences a cardiac arrest and dies. Hospital staff attempted to resuscitate Christopher until DNR was agreed by the consultant with Christopher's Mother.

5. Analysis of Practice

5.1.Key Time and Practice Episode 1

5.1.1. This episode covers the assessment and decision-making process that culminated in Christopher moving into supported living accommodation, followed by his first nine months there. Detailed planning for a move appears to have begun in late July 2014 following an initial meeting in February 2014.

5.1.2. In summary the learning from the analysis of this practice episode is that there were missed opportunities to support Christopher's transition into supported living and to explore with those who had detailed knowledge of Christopher how to respond to patterns of behaviour as they (re-)emerged.

5.1.3. From the available assessment documentation and the reflective conversations held with those staff who were involved at the time, Christopher had coped well with a six week stay in respite care whilst his Father recovered from surgery. This prompted his Father to consider Christopher "living independent of me." One key question, however, is what the concept of "independence" meant to those involved, especially Christopher. Christopher's Mother believes that Christopher did not have an understanding of the concept "independence." She has pointed out his dependence on others for many of the requirements of daily living.

5.1.4. Those who knew Christopher and his Father at this time have suggested in reflective conversations that it is difficult to know what Christopher's wishes were, partly because his Father spoke for him and partly because he did not understand the complexity of the move although he did appreciate the concept of his own room. It should be borne in mind that assessments up to this point of Christopher's mental capacity with respect to decision-making about medication, nutrition and accommodation had concluded that he did not have decisional capacity. It might have been appropriate to consider the appointment of an independent advocate for Christopher at this time to assist with discussion of this significant transition and in exploring how everyone understood independent living. At the learning event one conclusion reached was that there could have been more work done on exploring the differences in understanding around independence between Christopher, his family, and the agencies involved at the time.

5.1.5. The records indicate that Christopher's Father thought that residential care would be appropriate but that staff working for Bristol City Council Social Intervention Team assessed independent living as the more suitable option. No other options or alternatives were actually considered jointly between professionals and the family. Staff working in the Social Intervention Team have stated that they understood Christopher's Father to have concluded that a residential setting was not suitable. Equally, the decision that supported living was the best option for Christopher was influenced by the family's knowledge of the supported living provider and by the fact that he would be able to continue to engage in activities, such as day centre attendance. Both Christopher's Mother and Father have questioned the account taken of Christopher's complex medical problems and health care needs, and have questioned whether staff at the supported living provider had appropriate training and levels of knowledge and skills. The evidence from the supported living provider staff given at the inquest notes that they were not health care trained workers and were therefore deferring to medical, psychological and health care practitioners. Panel members and the independent reviewer have also questioned whether care staff were sufficiently qualified and experienced for meeting Christopher's needs.

5.1.6. Christopher was shown the property into which he eventually moved and had one taster weekend there. There is a difference of opinion between the family and the supported living provider as to whether there were other introductory events prior to him moving in

permanently. Family members are adamant that there were none. There does appear to be agreement that Christopher was enthusiastic about his move and that he was fully involved in choosing furniture and furnishings for his bedroom. One ground for optimism was that he liked the house and knew one of the other residents who would be living there. Another was that the supported living provider specialised in supporting adults with learning disabilities, including those with challenging behaviour and physical health care needs. There does appear to have been a good handover of information from the family to the supported living provider with respect to Christopher's routines regarding personal care, eating, medication, supplements and preferred day-to-day activities, including the need to act quickly in the event of Christopher showing signs of dehydration.

5.1.7. If some of the practicalities were taken care of adequately, it is perhaps surprising that a multi-disciplinary or multi-agency meeting was not held in the run-up to the placement, involving professionals and agencies that had been providing day services and respite care, and the new provider of independent living, and the family. This should have been seen as essential. It would have facilitated the exchange of information, for example with respect to strategies for managing Christopher's darker moods and periodic refusals of medication and nutrition, which his respite care placement had had fully in place. It might also have enabled some clarification of Christopher's decision-making capacity, for example his ability to understand the implications of refusing medication and nutrition. Again, his respite care placement had clearly documented his lack of capacity with respect to food and drink intake, and medications. It might have enabled some contingency planning since it was known that Christopher's response to difficult situations and transitions was sometimes to withdraw. It might have enabled earlier involvement of specialist practitioners to proactively support Christopher through the transition. It might have enabled the new provider to appreciate more fully the challenges that Christopher might present, for example around refusals of medication and nutrition, and then to assess not just his compatibility with other residents but also with the philosophy, approach and level of specialist care on offer.

5.1.8. A further question remains about the emotional impact of the change for Christopher and his Father, and how Christopher in particular understood and experienced the move and the concept of independent living. His Father has expressed the view that Christopher was becoming more familiar with being away from home for longer periods as a result of stays in respite care, and that he was becoming more comfortable in respite care and also at college and day services. However, it is very different, arguably, knowing that one is away from home for a limited period of time rather than moving away permanently. It is not clear that anyone really worked with Christopher to understand how he experienced the move in the abstract and then in the reality.

5.1.9. This conclusion is reinforced by an assessment by Bristol City Council staff dated 10th September 2014, of which the family was not made aware. This records that Christopher might struggle with the transition from living with his Father to living by himself. It further notes that he liked routine and could sometimes feel low and experience anxiety, which he found it difficult to talk about. The assessment notes that he could become particularly anxious about his Father and that this anxiety could affect his eating and drinking. He had in the past been admitted to hospital to be rehydrated. According to the family, the last time Christopher had

been admitted for rehydration was in 2000/2001. It is the family's view that none of those concerns about transition were raised at the time.

5.1.10. From the reflective conversations with staff involved at the time emerges a theme of loss, which may not have been recognised and appreciated at the time. The move entailed a major life change for Christopher, moving from a living situation of some quite considerable and arguably necessary control to another where he was offered considerable and, perhaps, even too much choice. It has been suggested that Christopher, as a young man, wanted everyone to understand that he wanted control and autonomy, but also that undue weight was given to his autonomy and self-determination. Christopher's family, especially his parents, have suggested that he did not feel abandoned but that he was, to some degree, deprived of his support system. They recognise that his refusal to take medication and to eat and drink may have been a lever of control, the exercise of some power to say "no." However, this was a pattern that had long been recognised and for which previous providers of respite care, as well as the family and the supported living provider initially, had management strategies. As the family and practitioners attending the learning event have pointed out, moreover, he would not have understood the consequences; he did not have the capacity to think through and analyse what would happen as a result of exercising this control.

5.1.11. The balance between autonomy and a duty of care is often difficult to strike. It is perhaps not surprising, therefore, that on reflection the move proved more difficult and complex than anyone anticipated. No psychological or emotional support appears to have been offered to either Christopher or his Father to navigate this major relationship as well as habitation change, both in the abstract (anticipating the change) and the reality (once the move had taken place). This might have uncovered more about how they both felt about the move, how they experienced it, what worries and anxieties they might both have had, and whether it was what either or both of them wanted. Equally, partly because there were no meetings of all the professionals who knew Christopher together with the family to discuss how to manage potential risks and to formulate contingency plans, there was no agreed approach in place to address difficulties, such as his low and darker moods, when they emerged.

5.1.12. Initially after the move Christopher appears to have settled well. However, at the beginning of November 2014 he did not want to attend his day centre. Later in November mood swings are reported and in early December he is verbally abusive to staff. It is suggested that he is finding adjustment "tricky" and that he might be depressed. He is referred to BIRT[14] and at the end of January is assessed by a Psychiatrist as moderate risk to self as a result of refusals of medications and nutrition. It is recommended that his moods are monitored. Mood charts are again suggested by Bristol North CLDT on 23rd November 2015. It has been suggested in the reflective conversations that staff at BIRT might have offered something to Christopher to support his transition to independent living, especially as his behaviour was seen as evidence of adjustment difficulties and a possible depressive reaction. At the learning event it was noted that two BIRT staff had worked with Christopher when he was previously accessing respite care and that there had been meetings between family members and professionals working with

[14] Family members have stated that they were unaware of BIRT until October/November 2015.

Christopher to support him. This did not happen in the early stages of his placement at the supported living provider and BIRT staff involvement in November 2015 represented a late referral and a missed opportunity.

5.1.13. Attendance at the day centre becomes an issue again in mid-February 2015 and results in a change of provider. Thereafter Christopher appears to settle again and in May the psychiatric assessment is that the risk has reduced. The mood and ABC charts have noted improvements and so Christopher is discharged by Bristol North CLDT.

5.1.14. One question that arises here is how these early incidents were understood by those involved with Christopher. He is already becoming difficult to manage in the mornings by early November 2014. Some of his verbal aggression appeared to follow contact with his family although it should also be remembered that he was happy following other contacts with his family. How was this understood and how was it explored with Christopher? Was this further evidence of something like ambivalence about the move? If so, perhaps this was a missed opportunity to explore how the transition to independent living was progressing. Were the current behaviours sufficiently linked to what was known historically about Christopher and factored into a risk assessment?

5.1.15. Another is whether sufficient weight was given to known history. A social care assessment in 2011 comments on Christopher's behaviour being a protest against abandonment. The behaviours in November and December 2014 and in February 2015 might have been evidence of a pattern of response, which earlier assessments had captured quite clearly. His refusals to attend a day centre and to take medications, supplements, drinks and food might have been evidence of frustration or anxiety.

5.2.Key Time and Practice Episode 2

5.2.1. This time and practice episode explores the deterioration in Christopher's situation between August 2015 and his admission to hospital on 4th December 2015.

5.2.2. In summary the learning from this episode includes insufficient use of historical information for managing Christopher's behaviour, lack of coordination of the involvement of the different professionals involved, absence of placement review and a clear plan to address a deteriorating situation, and failure to convene meetings of all those involved and concerned about Christopher. There was confusion about roles and responsibilities, and about whether or not Christopher had mental capacity with respect to decisions about nutrition, hydration and medication.

5.2.3. The key concern that emerges from the combined chronology is his increasing aggression towards staff and his refusals of medication, supplements, drinks and food. By one estimate, there were over 70 such refusals in this period, amounting to self-neglect[15]. As is evident from

[15] Self-neglect can comprise, with respect to individuals with and without decision-making capacity, neglect of self-care that significantly endangers wellbeing (Braye, S., Orr, D. and Preston-Shoot, M. 2014 *Self-Neglect Policy and Practice: Building an Evidence Base for Adult Social Care*. (2014) London: Social Care Institute for Excellence). Family members have expressed the view that Christopher was not capable of self-neglect and that events within this time episode represent organisational neglect.

the combined chronology information was regularly exchanged between staff employed by Bristol City Council Social Intervention Team, The supported living provider, BIRT and the Bristol North CLDT, and the GP, sometimes but not always including Christopher's Father.

5.2.4. The dangers of Christopher's refusals of medication, hydration and nutrition are clearly documented, as are approaches to managing that behaviour, for example by the provider of respite care before Christopher moved into The supported living provider, and in social care assessments and medical assessments that predate the period under review here. It is questionable whether sufficient regard was paid to this historical information.

5.2.5. Christopher is reported as saying occasionally that he was unhappy, that he wanted to move, and that he was angry. It does not appear that anyone seriously explored the appropriateness of the placement at this stage as a result of these statements or explored in any detail what he was angry, anxious or unhappy about. It is also unclear who might have seen this as their responsibility and whether any methods of communication were used in addition to conversation in an effort to appreciate what Christopher was feeling and experiencing.

5.2.6. Indeed, the inquest transcript reveals that, although the Bristol City Council Social Intervention Team practitioner saw her role as an "umbrella person" in order to promote communication between the supported living provider and the family, she was unclear about the term keyworker. Participants at the learning event observed that someone did need to coordinate the case at this time. The panel have concluded that the absence of such coordination and formal review of the placement represents a significant oversight.

5.2.7. It is unclear what may have changed that precipitated the deterioration. A 2013 social care assessment recorded that Christopher would find it difficult to be with noisy people and that he would be affected by the moods of others. It is not clear whether Christopher's relationships with the other residents changed, for example when the third resident moved in. There is some suggestion, and it is a frequently told story in this case, that Christopher liked hospitals and did not want to leave Southmead Hospital in August 2015. However, is this coincidental as Christopher's refusals of personal care, medication and hydration/nutrition do not emerge significantly for at least another month? Family members have observed that Christopher did not routinely obsess about hospitals. However, statements to the inquest highlight how Christopher's mood changed significantly after this hospital discharge and the family's perception is that relationships changed between them and some of the supported living provider staff, and between Christopher and some staff.

5.2.8. It is questionable whether, as events unfolded, there was sufficient recognition of the historical pattern – Christopher had refused medications, drinks and food before – and what could be learned from those prior episodes. One significant exchange takes place over 17th and 18th November 2015. The GP clearly found Christopher to be dehydrated on 17th November and planned to admit him to the GP Support unit the following day. In the event this admission was cancelled as Christopher began to eat again and the GP had not been informed of a seizure that Christopher had apparently experienced. In its place the GP made urgent referrals to the

Psychiatrist and to the Consultant Gastroenterologist[16], noting that his weight has dropped by 5kg[17]. At the inquest the GP gave evidence that, had she known of the seizure, this would have made the admission more likely than not. Further reflection from the GP has been that non-admission was possibly over-optimistic, based on the possibility that a psychological intervention could be found to address the issues underlying Christopher's behaviour.

5.2.9. A question to be asked is whether, given the history, too much regard was paid to Christopher taking some food rather than the longer-term pattern of refusal, acceptance and refusal[18], alongside too little regard for on-going and perhaps increasing disagreement about his diet, and exploration of his moods/emotions. Earlier assessments, from 2013 if not before, had charted that anxiety affected Christopher's health and that it was important to act quickly if he stopped eating and drinking because his diet affected his mood, physical health and willingness to cooperate. Admission may not necessarily of itself have enabled consideration of these issues but neither did the course taken.

5.2.10. It is questionable too whether there was sufficient urgency, given that prior medical and social care assessments had highlighted the dangers for Christopher if he refused medications, food and drink. For example, a referral to the Dietician is agreed on 16th September and made by the GP in early October but the debate about his diet is not really settled before Christopher is admitted into hospital for the final time in early December 2015. He had not seen the Dietician by then, possibly because of a shortage in community dieticians. Further mood and ABC charts are recommended in November, repeating something done previously, but this may have delayed a multi-agency approach, with the family involved also, in thinking through the meaning of his behaviour. Christopher may have had his first seizure for some years on 16th November but this does not appear to have prompted a review of his medication refusals. The GP requested an urgent gastroenterologist review on 25th November but this did not take place before Christopher was admitted to hospital on 4th December 2015. The urgent appointment was in fact scheduled for February 2016.

5.2.11. A safeguarding referral was not made until the middle of November despite the known seriousness for his health and wellbeing of Christopher's refusals and when there had been a serious deterioration in the situation over the previous six weeks. The supported living provider staff were regularly sharing concerns with the GP and with Bristol City Council Social Intervention Team. Christopher's allocated worker in that team received at least six email communications from the supported living provider between 7th October and 2nd December 2015 but no major change in approach resulted. There was no multi-agency meeting that brought all those involved with Christopher together, including the family. There is a link here to observations made earlier that no-one saw it as their role or responsibility to act as a keyworker in this case. A professionals meeting on 23rd November appears to have agreed that

[16] As noted elsewhere in this report, a response to the urgent referral was not scheduled for several months.
[17] His weight was 46 kg on 23rd March 2015, 45.6kg on 1st May 2015 and 39kg on 10th November 2015. At the time of his death Christopher weighed 35kg.
[18] Another Serious Case Review also found that staff accepted that any food was better than none and an absence of plans to manage food refusal within a best interest framework (Suffolk Safeguarding Adults Board (2015) James.

the supported living provider staff should speak with Christopher's Father about his son's mental capacity and best interest decisions regarding management of medication and his nutritional intake. This never actually happened. Christopher's allocated worker in the Social Intervention Team did meet with Christopher's Father just before his final admission to hospital to discuss the approach to be taken to his health needs.

5.2.12. The supported living provider staff were advised by BIRT staff on both 16th and 17th November 2015 to make a safeguarding referral. This was done on 17th November but the referral was screened out on the grounds that Christopher was being monitored by his GP, BIRT and the Bristol North CLDT Psychiatrist. As several reflective conversations observed, this was disappointing as it may have helped to explore the situation and to clarify options. It would have brought all the parties together to clarify roles, and share responsibilities, risks and options. Another safeguarding referral could have been made subsequently but perhaps those involved were deterred from doing so because of the reasons given for screening out the first such referral. At the learning event, those involved at the time discussed whether more agencies should have made safeguarding referrals at the same time, as well as subsequently, or whether they should have more actively supported and endorsed the one referral that was made.

5.2.13. It is possible that not all the current and historical information and assessments were available. It is the case that the referral is quite sparse in the information provided about the extent of Christopher's self-neglect and the challenges being faced by staff. Nor was the information provided clearly enough alongside the three criteria[19] in Section 42 of the Care Act 2014 that would trigger an enquiry. That said, it is arguable that the criteria were actually met. Acceptance of the safeguarding referral would have opened up discussions about Christopher's mental capacity, risk assessment and possible legal options, including referral to the Court of Protection. Indeed, one facet of this case is that at no point do legal options, such as referral to the Court of Protection, appear to have been considered.

5.2.14. As footnote 12 has stated, family members do not recognise the term self-neglect in respect of Christopher's behaviour. The panel and independent reviewer have reflected that it is possible that professionals working with Christopher may have understood the term as only applying to individuals with decision-making capacity. However, as the same footnote observes, the term self-neglect may be applied to individuals without decision-making capacity whose behaviour may result in significant harm to their wellbeing and is often characterised by reluctance to engage. Other Safeguarding Adult Reviews[20] have strongly advised that, where cases do not trigger a section 42 enquiry, there should nonetheless be a multi-agency, multi-disciplinary pathway where complex cases can be discussed and risk management plans agreed

[19] An enquiry must be undertaken, which the local authority can delegate to another party, where the local authority has reasonable cause to suspect that an adult (a) has needs for care and support, (b) is experiencing or is at risk of abuse or neglect (including self-neglect), and (c) as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it.

[20] Preston-Shoot, M. (2017) What Difference does Legislation Make? Adult Safeguarding through the Lens of Serious Case Reviews and Safeguarding Adult Reviews. A Report for South West Region Safeguarding Adults Boards. Bristol: SW ADASS.

and implemented. The panel has concluded that the absence of such joint working in Christopher's case is another significant oversight.

5.2.15. The inquest transcript also highlights other concerns about how those involved worked together at this time. There were very few measurements of Christopher's weight. The supported living provider staff did not weigh Christopher and did not think of requesting that this be done. They deferred to the GP who did not proactively state that they should regularly monitor his weight. BIRT staff gave evidence that weight monitoring was a role for the supported living provider staff but may not have specifically advised that. It is therefore unclear at times how much weight he was losing.

5.2.16. If monitoring his weight emerges through inquest evidence as having been seen as someone else's responsibility, so too does capacity assessment. The supported living provider did not see mental capacity assessments as part of their role. The GP looked towards Psychiatry for detailed assessments of Christopher's mental capacity.

5.2.17. A sense emerges from the inquest transcript and some of the reflective conversations of everyone looking for guidance from someone else. The supported living provider evidence suggests that staff were looking for guidance from the Social intervention team, BIRT and the GP. The GP was looking for support from BIRT and Psychiatry with respect to determinations about Christopher's mental capacity and to address what she saw as behaviour that had psychological determinants and therefore a psychological resolution. This highlights the significance of the omission of convening a multi-professional, multi-agency meeting. Concerns were escalating and yet a clear plan did not result, for example regarding how to manage Christopher's nutritional support in the community, especially as the supported living provider staff could not force him to eat and drink.

5.3.Key Time and Practice Episode 3

5.3.1. The third time and practice episode runs from Christopher's admission into hospital on 4th December 2015 until his death on the 22nd December 2015.

5.3.2. Key learning from this episode includes the importance of parity of esteem, namely giving equal regard to, and considering together a person's mental and physical wellbeing, and of following through on discussions initiated with the family about treatment approaches, especially DNR.

5.3.3. He was dehydrated and malnourished on admission, with weight loss and hypertension, according to the GP who requested the urgent admission. A mental capacity assessment with respect to his decision-making about nutritional intake was completed on 6th December. One with respect to his decision-making concerning medications was completed on 7th December. Both assessments concluded that Christopher did not have decisional capacity. A meeting to determine his best interests was held on 9th December. Family members were involved in this meeting, which discussed options including naso-gastric feeding, IV fluids, and sedation if necessary. The risks of this approach were discussed, including aspiration pneumonia due to Christopher's poor mobility, frailty, low weight, naso-gastric feeding and general anaesthetic. There was also discussion with family members after the best interest meeting to clarify and

agree on the use of mental capacity as opposed to mental health legislation, and the rationale for the use of Deprivation of Liberty Safeguards.

5.3.4. Deferring implementation of more intrusive interventions to ensure that Christopher was receiving his medications and an adequate nutritional and hydration intake followed the principle of proportionality and the least restrictive alternative, hoping that simple, supportive and non-restraining techniques would lead to progress. It is clearly documented, and emerged from reflective conversations also, that those treating Christopher did not believe that it was clear or practical that actively and assertively treating him was the right thing to do. However, this meant that he accepted limited hydration and nutrition, and was still refusing medications until a PICC line was inserted under general anaesthetic on 13th December.

5.3.5. Had mental capacity assessments been undertaken immediately upon Christopher's admission to hospital, and had a best interest multi-professional and multi-agency meeting been convened immediately thereafter, that might have facilitated a transparent risk assessment, namely early discussion about how long to persist with supportive and encouraging techniques, to persuade Christopher to accept medications, food and drink but with the risk that he would continue to refuse, before opting for more interventionist options that also carried risks. The family feel that Christopher's condition was such on admission that these processes of proportionate intervention leading to a more assertive stage should have taken place over a much shorter period especially given his pre- admission condition and history. The family saw the hospital admission as the best opportunity to save his life.

5.3.6. The medical perspective that emerges from the inquest transcript and reflective conversations was that the family's perspective that something had to be done immediately was understandable but that ways forward were complicated because of the associated risks, for example with respect to sedation and the bowel's possible difficulty in coping when Christopher's nutritional intake increased, with a high risk of re-feeding syndrome. Although Christopher's condition on admission was an obvious concern, for the treating physicians he did not appear critical, with for instance good blood test results and therefore, in the circumstances, a least restrictive and cautious approach was appropriate because it was difficult to know how interventionist to be.

5.3.7. It is understandable that, having raised their concerns and suggestions, family members acquiesced to the medical perspective. It appears, however, that they were unaware of options potentially available to them in the absence of agreement amongst all those involved about how to act in Christopher's best interests, namely exploration of referral to the Court of Protection.

5.3.8. One reflective conversation has observed that Christopher was at times on noisy and busy wards and that liaison nurses might have done more to question this, especially since Christopher was known to dislike noise. However, a reasonable adjustment assessment was completed shortly after his admission and Christopher was also known to like hospitals.

5.3.9. More positively, there does appear to have been a good handover of information between the community and hospital dietician, and between Bristol North CLDT and BIRT staff with the hospital. The Learning Disability Nurse had known Christopher previously and was aware of

historic issues relating to food intake and behaviour. Family members were enabled to give advice about how to communicate with Christopher, namely to give him opportunities to engage and time to process information. Learning disability, medical, dietician and nursing assessments were done after admission and reviewed thereafter.

5.3.10. There were no immediate complications after the insertion of the PICC line. Bloods taken showed that he had good renal function. He was reviewed on 17th December by a Consultant Hepatologist when Christopher was already on antibiotics for a chest infection confirmed by X-ray. The Consultant was very concerned about the long-term strategy regarding nutrition and so referred Christopher to the Consultant Gastroenterologist. He was transferred to a luminal gastroenterology ward. On the 18th December he was seen by the Dietician to ensure correct nutritional support and by a Consultant Psychiatrist. The plan was to continue with enteral feeding to encourage oral intake. There were no new psychiatric issues. Advice was given by the Learning Disability team. Christopher complained of a very sore abdomen and only reluctantly allowed examination. There was some abdominal distension. On 21st December he was reviewed by the Learning Disability Nurse, Dietician and Consultant Gastroenterologist. He had persistently raised CRP, suggesting inflammation despite intravenous antibiotics. He had a tender distended abdomen. He had X-rays and another possible cause for raised CRP and abdominal pain, namely a blocked shunt, was considered, resulting in a CT scan. The day he died Christopher initially seemed happy but was later incontinent of urine and complaining of abdominal discomfort. A bladder scan could not be done before he died.

5.3.11. An impression from reading the combined chronology and the reflective conversations is that Christopher was being closely monitored by a range of medical and health care practitioners. For example, his nutritional intake was being monitored and was gradually increasing, with the risk of re-feeding syndrome being considered. Different options with respect to his abdominal pain were being explored. However, less obvious is how all these assessments and reviews, including of his emotional wellbeing and mental health, came together and the impact of his emotional health on his physical wellbeing and vice versa. Thus, what significance was attached to what Christopher, unknown to his family, was saying about not wanting to get better because that would mean a return to his placement? What steps might have been taken to exploring this with him so that he might have felt that he was being listened to? As highlighted by one staff member involved with Christopher during his last hospital admission, mental and physical wellbeing need to be considered together.

5.3.12. The hospital chronology documents that on 13th December the family had agreed on a “do not resuscitate” approach on the ward, following discussion initiated by a medical consultant, and informed nursing staff of their decision. The chronology also observes that relevant documentation had not been completed and lodged in nursing records. The panel and independent reviewer have been informed that Christopher’s medical records do not contain signed “do not attempt CPR” documentation and it appears that medical practitioners did not complete the formalities necessary for DNR. Christopher’s mother has stated that the family had informed the hospital of their wishes and that their decision had either not been placed in Christopher’s notes or not acted upon. In the event after three unsuccessful attempts, resuscitation was stopped by the consultant in agreement with Christopher’s mother but the absence of completed and signed documentation following the family’s communicated decision

in response to information provided by a doctor is a serious and, for the family, a distressing omission[21].

6. Findings – Themes across the Time and Practice Episodes

6.1.Finding 1

6.1.1. Family involvement is one theme that spans the entire period being reviewed. The key learning point here is that the degree and nature of family involvement was never clarified, nor kept under constant review.

6.1.2. In October 2014 Christopher's Father relinquished his role as Christopher's main carer in order to support his son to live more independently. It has already been noted that little or no support was offered to him to explore what this transition involved for him. There was no meeting of everyone at the outset to scope out family involvement in the context of independent but supported living. Thereafter, Christopher's Father and other family members attended various meetings and consultations at which Christopher's physical and mental health needs and behaviours were discussed. They contributed their knowledge, understanding and advice about his history, diet, health, interests and mental capacity. At times they were involved in trying to persuade Christopher to take his medications and to accept nutritional supplements, drinks and food but at other times they were criticised for being too involved and controlling, and for undermining the routines being followed by the supported living provider and Christopher's independence. It would have been helpful and good practice to have outlined expectations of family involvement from the outset and to have kept this under constant review.

6.1.3. There was insufficient appreciation that Christopher's Father and other family members might have been worried about the approach being taken towards Christopher. Equally, they may have struggled to give up their previous approach to Christopher despite their investment in making the transition to independent living a success. Family members had had long experience of managing the risks associated with Christopher's complex health care needs. Now Christopher was living in a context where there was an emphasis on promoting his independence. As emerges through the inquest transcript, the approach within the supported living provider and the Social Intervention team was to give Christopher as much choice and control as possible. As other Safeguarding Adult Reviews have observed[22], family members may, on the basis of their lived experience, have strong views about what they regard as the appropriate extent and nature of support for a particular individual. As in Christopher's case, family members may believe an individual's agency, mental capacity and choice to be more

[21] It is also possible that the family regarded their agreement with a DNR approach as covering all aspects of Christopher's care and clinical presentation whereas hospital staff might have seen it as applying to a narrower set of circumstances and/or as requiring review dependent on the medical circumstances at the time. This highlights again the importance of paying particular attention to family involvement, including being clear about the requirements of the Mental Capacity Act 2005.

[22] For example, Gloucestershire Safeguarding Adults Board (2017) Safeguarding Adult Review – Hannah; Somerset Safeguarding Adults Board (2016) Safeguarding Adult Review – Tom; Suffolk Safeguarding Adults Board (2015) Serious Case Review - James.

compromised than practitioners appreciated. Notwithstanding the importance of paying due regard to self-determination, this has to be considered alongside an informed understanding of an individual's decisional mental capacity and the evidence that family involvement can be supportive. Had meetings involving family members and practitioners been instituted from the outset and held regularly, a consensus position could have been established about how to manage Christopher's needs and how to respond to occasions when he was perhaps seeking to assert greater independence, for example regarding what he chose to eat. The challenge of balancing a person's autonomy with a professional's duty of care to protect people from foreseeable harm emerges both from Safeguarding Adult Reviews and research[23]. Practice should include respectful challenge and exploration of the extent to which choice is really chosen, without seeking to deny a person's wishes and feelings. Such practice requires dialogue and interaction. Similarly, although Christopher had a right to private life (Human Rights Act 1998) and was therefore entitled to confidentiality, that right may be qualified according to law, with for example information shared to safeguard the person from significant harm. The panel and independent reviewer have concluded that the absence of "whole system" meetings to consider how to manage these challenges is a significant oversight.

6.1.4. The response when Christopher began to say that he did not feel listened to and did not want such frequent family visits was not timely. It appears that no formal discussions were held until early December 2015 regarding how involved Christopher's Father and other family members would be. When disagreements were clearly emerging, for example in October 2015 and subsequently, about Christopher's diet, when family members were expressing concern about Christopher's loss of weight, and when family members were perceived as not respecting Christopher's space, an early meeting to discuss these issues would have been helpful. It would have brought everyone together and hopefully ensured a consistent management plan. As it was, no family member attended the professionals meeting held in November 2015 because they were not invited. Whilst this accords with standard practice with respect to professionals meetings, the absence of meetings with family members meant that they did not necessarily hear about plans for Christopher or have a sustained opportunity to contribute to them. There was no opportunity within which the confusion or disagreement about Christopher's diet between the family, the supported living provider staff and the health care professionals involved could be discussed by everyone meeting together. As one reflective conversation observed, Christopher would have been aware that professionals and carers were sometimes, at least, going against what his Father, whom Christopher trusted, thought appropriate with respect to his diet. At these times of conflict or disagreement, Christopher became noticeably lower in mood. As acknowledged at the learning event, there was no sustained opportunity to consider with the family their expectations alongside what Christopher was perhaps wanting because meetings were not a routine part of the care plan. There was no opportunity to agree on the parameters of family involvement in respect of an individual with complex needs and

[23] Preston-Shoot, M. (2017) 'On self-neglect and safeguarding adult reviews: diminishing returns or added value?' *Journal of Adult Protection*, 19 (2), 53-66; Braye, S., Orr, D. and Preston-Shoot, M. 2014 *Self-Neglect Policy and Practice: Building an Evidence Base for Adult Social Care*. (2014) London: Social Care Institute for Excellence.

increasingly challenging behaviour. The panel has concluded that this represents a missed opportunity.

6.2.Finding 2

6.2.1. A second theme is person-centred care. The key learning point here is the centrality of relationship-based work, drawing on the opportunities that Christopher offered, informed by the understanding from those who knew him best. Throughout the chronology and the other documentation made available to the review, one captures glimpses of how Christopher experienced his world. He tells people that he feels low and shaky, not listened to, and that he wants to move. He also says that he is happy where he is living. At times he says that he wants to see his family less. However, these are essentially glimpses. The daily logs from the supported living provider compiled by staff refer to "chats" but little can be gleaned about what was talked about at those times. No-one appears to have built up and sustained a relationship with Christopher over time and to have talked with him, for example about his move, living away from his family home, his hopes and any confusions. No-one appears to have considered using techniques and tools other than conversation in an attempt to understand what Christopher was experiencing and feeling. As a result we have to discern from his behaviour what he may have been experiencing.

6.2.2. One example relates to his diet. There are discussions between professionals, involving the family, about weaning him off supplements and allowing him to eat "normal food." It has already been noted that there was disagreement between the family and some of those working with Christopher about the content of his diet and that this should have been the focus of a review meeting. Here the point to question is how Christopher saw this change. How was it presented to him? What sense was he helped to make of any disagreements about his diet?

6.2.3. Another example relates to the prescription in November 2015 of medication in response to his depression. Both before and after this prescription Christopher is saying to those involved with him that he does not want to get better. He is giving mixed messages about contact with his family and his placement at the supported living provider. His mood is lower when care staff and his Father are discussing what nutritional intake is best for Christopher. This would have been the occasion to attempt to work with Christopher in some depth to understand the meaning of his emotions, as well as to bring everyone involved together to discuss a way forward.

6.3.Finding 3

6.3.1. A third theme that threads through all three times and practice episodes in this case is that of mental capacity and the emphasis on independence. Key learning here is the importance of practitioners understanding and correctly applying the law regarding mental capacity. At times it appears that Christopher was allowed to assume responsibility in areas that he could not manage. Respect for choice has to be balanced with a duty of care.

6.3.2. Social care assessments completed prior to the period under review here concluded that Christopher could not cope with too many options and that he would become confused if given too many choices. He would need support for important decisions. That assessment remains the family's perspective. Family members have pointed out that it was important to phrase

questions to Christopher carefully, given his disabilities, in order to appreciate his perspective as accurately as possible but also act in his best interests. They have offered two examples in particular where this may not have happened. One is with respect to how options were presented to him regarding what he might have to eat and drink. The second is with respect to the insertion of a cannula when in hospital in December 2015. He had prior experience of cannula insertion and had previously not objected.

6.3.3. Bristol City Council Social Intervention Team appear to have carried out a mental capacity assessment prior to Christopher's placement and concluded that he did not have capacity to enter into a tenancy agreement. It is less clear whether there was any formal assessment of the degree of his understanding of independent living. Presumably his move into supported living was a decision in his best interests[24]. It remains questionable, therefore, as to what level of independence he could actually manage.

6.3.4. To some degree from the reflective conversations and the evidence given at the inquest there emerges an inherent contradiction in the approach being taken towards independent living. Christopher was being told that he was living independently and could make choices but to varying degrees at different times these choices were being curtailed and he was being criticised for the unwise choices he made, for example his response to episodes of double incontinence. It is unclear whether any limitations to his ability to make decisions were discussed with Christopher. Equally, explicit adjustments do not appear to have been made by the supported living provider and Social Intervention Team staff to their philosophy of independent living to reflect an understanding of the limitations to Christopher's mental capacity to take particular decisions. For example, it is unclear what adjustments, if any, were made after a BIRT assessment in mid-November 2015 that Christopher did not have decisional capacity regarding medication.

6.3.5. Mental capacity assessments should be time and decision-specific. GP records for 21st August 2015 contain discussion of mental capacity, concluding that Christopher was able to make small decisions but did not have the mental capacity to take decisions about his care. Twice in September 2015, however, GP records do not contain any reference to whether he does or does not have capacity to refuse medication or to decide about his nutritional intake. He is recorded as having fixed ideas about what he can and cannot be asked to do, and as being defiant on one occasion that he will not take mediation. This was one occasion when, in light of Christopher refusing medication, supplements, drinks and/or food, a multi-agency meeting could have been held, to discuss the increasing challenges presented by his behaviour and to share understanding about his refusals, with legal advice available so that all options going forward were considered. Indeed, noticeable by its absence is any consultation with legal professionals with respect to options in law for managing this situation.

6.3.6. Christopher had been assessed as not having decision-making capacity with respect to his finances. Nor did he have the mental capacity to agree to a referral to the BIRT team. His lack of capacity to understand the risks of refusing medication, food and drinks was one trigger for the

[24] The case of James (Suffolk Safeguarding Adults Board, 2015) raises similar questions with respect to a learning disabled adult with additional disabilities, including a life-long bowel problem.

safeguarding referral. On 27th November 2015 BIRT staff assessed him as not having an understanding of the importance of taking his medications. A Psychiatrist had also assessed Christopher in mid-November 2015 as not having capacity regarding decisions about his medication. Significantly, at the inquest, the supported living provider staff stated that this assessment did not alter their approach. However, if medication could not be given by them in his best interests, that should have triggered a multi-professional and multi-agency meeting to discuss options, including possible referral to the Court of Protection. On 1st December the GP considers his mental capacity with respect to why he wanted to be admitted to hospital and was refusing medication.

6.3.7. At other points, for example on 27th November and 2nd December 2014, and again on 10th November 2015 there is no record of Christopher's mental capacity having been discussed. On 27th November the records indicate that BIRT staff completed an informal mental capacity assessment but it is unclear what "informal" means in this context and why a "formal" Mental Capacity Act 2005 assessment was not undertaken at this point. The inquest transcript contains evidence from BIRT and Bristol City Council Social Intervention Team staff that there was no formal mental capacity assessment regarding his decision-making about nutritional intake. Assessment is presented therein as on-going because his decisional capacity was perceived as fluctuating. It was accepted at the inquest that at this time he did not understand the full consequences of his actions, for example of how ill he would become but it was also asserted that the on-going nature of the assessment was designed to give him opportunities in order to be able to support him and not to take all control away from him. To remove all control was thought to be prejudicial to his mental health. However, the "informal" or on-going nature of mental capacity assessment with respect to nutritional intake resulted in deferred decision-making since no boundaries were placed around the process. Assessments should be both decision and time specific.

6.3.8. Christopher may indeed have had capacity, with the availability of considerable support, to take small decisions, dependent on his mood and physical health, and who was present at the time. However, some of the reflective conversations have concluded that greater emphasis should have been given to his mental capacity with respect to decisions about nutrition and medication, because he was not (fully) aware of the complications of malnourishment and dehydration, and that those involved should collectively as well as individually have considered best interest decisions and contingency plans. To the degree that there was confusion about the care plan for Christopher, this might have been caused by uncertainty about the Mental Capacity Act 2005, who was responsible for conducting assessments with respect to different decisions that he faced, and the absence of meetings at which all those involved met together to discuss how best to meet Christopher's care and support needs and enhance the level of independence that he could reasonably manage.

6.3.9. A referral to enlist the involvement of an advocate was made on 25th November 2015 in response to difficulties balancing family involvement with the approach to maximise Christopher's independence, and to ensure that Christopher's wishes were fully understood. The family were not asked about or involved in this decision. Family members believe that Christopher's physical and mental health were extremely diminished at this stage and therefore query what value there was in this referral. The advocate attempted unsuccessfully to see

Christopher on 3rd December 2015. One reflective conversation suggested that a potential role for an advocate was not appreciated earlier and perhaps this was because of a lack of understanding of the Mental Capacity Act 2005 at the time. There were certainly grounds for considering the involvement of an advocate much earlier on.

7. Additional Learning

7.1. Good practice identified

7.1.1. Comprehensive information about Christopher was made available to the supported living provider at the outset of his placement.

7.1.2. Appointments to review Christopher's different physical disabilities were kept routinely and clearly document his progress.

7.1.3. Information from community teams was shared with hospital clinicians when Christopher was admitted in December 2015.

7.1.4. Hospital records note clearly the outcome of mental capacity assessments and best interest discussions.

7.1.5. Hospital dietician records are particularly clear about the approach to be taken to meeting Christopher's hydration and nutrition needs, with risks and the treatment plan outlined.

7.2. Learning point 1 - supervision

7.2.1. In any safeguarding adult review it is important to try to answer "why?" questions, to explore the "causes of causes." In this case there were a number of influential stories that were told by the professionals involved. Stories are narratives that people tell about themselves, other people and the contexts in which they live and work. These narratives communicate beliefs and values. The stories that are told can result in other potentially useful stories being left untold or unexplored[25].

7.2.2. One such story was that anxiety affected Christopher's health. There is no reason necessarily to doubt this assessment but it obscured another possible story, namely that Christopher was aware of his health and that his variable health affected his moods and anxiety state. Family members believe that his awareness of his health was limited but that his health certainly did affect his moods and anxiety state.

7.2.3. Another told story was that Christopher's behaviour was a form of communication and that what he was working out was the scope of his independence, the professional response to which was to maximise his choice and control. However, this way of seeing the situation potentially obscured the extent of his decision-making capacity, linkages with anxiety and low mood, and the fact that how choices were actually presented to Christopher could create the answer wished for. For example, Christopher's Mother has said that Christopher could become very negative and that at these times he needed to be encouraged to do something positive.

[25] Pearce, W.B. and Cronen, V. (1980) Communication, Action and Meaning. New York: Praeger.

Family members believe that Christopher refused hydration and nutrition because he was given too much choice to do so.

7.2.4. Another influential story was that of independence but this could mean different things to different people and what it actually meant from different people's perspective was not explored and worked through. There was also an understandable investment in the placement succeeding. However, this investment led to a disinclination to explore how Christopher was experiencing it. Although from later on in the second episode and again in the third time episode when Christopher was in hospital, The supported living provider suggested that the placement was no longer appropriate, this was not discussed with his family or in depth it appears in professionals meetings.

7.2.5. The importance of supervision lies in part in the ability of the supervisor to explore both the stories being told and those that are not being considered. Reflective conversations involving Bristol City Council Social Intervention team and learning event discussions would suggest a review of the content of available supervision, which needs to be challenging as well as supportive. When social care staff are inexperienced, with limited training, either generally or in relation to handling complex and challenging cases, management of staff and supervision are especially critical. So too is regular review by commissioners and providers that staff have sufficient knowledge, skills and experience to meet people's needs. The panel and reviewer have concluded that there are systemic lessons to be learned here from this particular case.

7.3.Learning point 2 – staff knowledge, skills, experience and training

7.3.1. However much information was shared with the supported living provider prior to Christopher's placement with respect to his past behaviours, this may well not have prepared staff there for the challenges that his complex physical and emotional needs presented. Nonetheless, it would have been sensible to have considered what knowledge and skills those supporting Christopher would need, especially as staff in respite care who had worked with Christopher prior to October 2014 were health care trained. Indeed the level of training and qualifications of the staff involved was scrutinised during the inquest. A focus here would have been beneficial both before the placement, on the basis of the needs that Christopher would bring with him, and subsequently.

7.3.2. As Christopher's complex needs emerged more clearly, especially from August 2015 onwards, even if on review then a decision had been clearly reached by everyone involved that the generic supported living placement should continue, detailed consideration should have been given to whether staff were appropriately trained to deal with his complex needs and how they might have been supported to deal with self-neglect. A review meeting in mid-September 2015 appears to have concluded that the supported living provider staff could cope at that point with Christopher's behaviour but this does not appear to have been revisited and it is unclear what robust strategies were in place to respond to his refusals.

7.3.3. The supported living provider staff, not being medically or health care trained, looked for guidance elsewhere as to how to manage his physical and emotional needs. As Christopher continued to refuse medications, supplements, drinks and food, and to express varying degrees of unhappiness, a sense emerges from the reflective conversations of a staff team struggling,

even overwhelmed. Although this was a caring staff team, some staff may have lacked skills, such as communication, active listening and working with people with specific diagnoses like autism. They may have struggled to see his aggression not as a personal attack but rather as a communication. The staff team were under pressure as to how respond to differences of view between the family, Christopher himself and the treating physicians with respect to his diet. Once again, a meeting at which all involved were present, including Christopher, would have enabled these tensions and dilemmas to be explored and plans devised to support the staff to look after Christopher.

7.3.4. The staff member in Bristol City Council Social Intervention Team who took lead responsibility for arranging the placement had, in the panel's view, insufficient training and proactive support to manage a case of this increasing complexity. It could be argued that she was best placed to act as the keyworker in this case, responsible for bringing all those involved together. However, from the inquest transcript it emerges that she did not really see that her role and responsibility extended beyond the arrangement and review of the placement. She did not have an understanding of the keyworker role. The panel's view is that placing the staff member in this position represents a significant organisational oversight. The panel has also observed that organisational restructuring around the same time, involving a move away from specialist teams, had an impact on how this case was managed. What is, arguably, certain is that someone should have had clear responsibility for bringing everyone together at crucial times within episode two. Equally clear is that organisations should keep under constant review whether the practitioners and care staff involved have the necessary knowledge and skills. Staff in this case needed more support and active supervision to manage the complexities involved.

8. Conclusion

8.1. No evidence of organisational abuse was found in reviewing this case. However, panel members and the independent reviewer have concluded that there was a lack of robust, effective individual and coordinated multi-agency work to manage his complex needs that had a cumulative impact and amounted to systemic organisational neglect[26].

8.2. There was no occasion in this case that all those who had worked with Christopher previously and those who were engaged with him during the time period under review were convened to share information and what they had learned about working effectively with him. There was no occasion when all those involved came together after August 2015 to consider all his physical and mental health needs together and to coordinate a strategy to minimise risks and to plan for contingencies. Other Safeguarding Adult Reviews have pinpointed the absence and the crucial importance of multi-professional and multi-agency meetings[27]. Coordination of efforts was missing in this case.

[26] This is understood as systematic poor practice derived from the structure, processes, policies, practices and culture of individual organisations and/or multi-agency partnerships. It is more likely where staff are inadequately trained and poorly supervised and supported (Department of Health (2017) Care and Support Statutory Guidance: Issued under the Care Act 2014.

[27] For example, Camden Safeguarding Adults Board (2017) Safeguarding Adult Review – YY.

8.3. The failure to hold meetings at the outset to focus on family involvement and the failure to convene such meetings from the beginning of the second episode onwards meant that some judgemental attitudes, as perceived by panel and family members, were allowed to prevail about the family without question. One example of this is how the approach that the family had taken over the years to manage Christopher's diet was described. If the routine that had been followed was "strict" it was because of an appreciation, agreed with medical practitioners over the years, about what would work well for Christopher. Whilst it might at times have been experienced by professionals as difficult to manage family expectations, more focused efforts to work with family members should have been attempted from episode two onwards.

8.4. There was an under-estimation of the support needed for Christopher and his family to enable a success to be made of transition to him living more independently. Whatever the transition between services and/or settings, Safeguarding Adult Reviews highlight the importance of emotional and practical support[28].

8.5. The Mental Capacity Act 2005 was at times misapplied. It is doubtful, for instance, whether Christopher could explain the consequences of his decisions regarding medication, hydration and nutrition during the months immediately prior to his final admission into hospital.

8.6. Christopher's condition on arrival at hospital in December 2015 and the subsequent management of his clinical presentation was complex and challenging. There is evidence of careful consideration being given to different treatment options. However, there are also lessons to be learned here too. One relates to how the DNR discussion was initiated and understood by all those involved, and then how it was not followed through. Another relates to what information the family was given about such options as referral to the Court of Protection if there was disagreement about how or in what way to act in Christopher's best interests. There are also questions about how closely Christopher's nutritional and medication intake was supervised.

8.7. The panel and the reviewer have considered the degree to which this case shines the light on systemic issues. Christopher was someone with very complex physical and mental health needs. There are others within the locality. The conclusion reached is that this case reflects wider challenges regarding thresholds for section 42 enquiries, the knowledge and experience of staff responsible for assessment and/or meeting people's care and support needs, and understanding and use of the Mental Capacity Act 2005 in relation to assessments and the use of advocates. The case also shines a wider lens on balancing autonomy against a duty of care, key working with adults with complex needs, the capacity of the supported living and care home market to accommodate people with complex needs and challenging behaviour, and the use of multi-agency meetings to consider safeguarding concerns. There may be insufficient understanding of best practice relating to self-neglect.

[28] For example, Havering Safeguarding Adults Board (2017) Safeguarding Adult Review – Ms A.

9. Recommendations to the Board

Arising from the analysis undertaken within this review, it is recommended that the Bristol Safeguarding Adults Board:

1. Reviews the application of thresholds for Section 42 (Care Act 2014) enquiries involving concerns about neglect and self-neglect, the guidance given about making referrals, and the feedback given to referrers.

2. Reviews the use of escalation routes when agencies are concerned about the screening out of a safeguarding referral.

3. Reviews the content and outcomes of single agency training on safeguarding referrals and procedures.

4. Reviews the content and impact of single agency and multi-agency training on Mental Capacity Act assessments, particularly with respect to individuals in independent and supported living, care settings and end of life pathways.

5. Undertakes a multi-agency case file audit on the standards of mental capacity assessments and best interest decision-making, particularly with respect to individuals in independent and supported living, care settings and in secondary healthcare settings.

6. Seeks reassurance from commissioners and providers on arrangements for ensuring that staff have the necessary knowledge, experience and skills for meeting the health, housing and social care needs of learning disabled adults with complex physical health and mental health needs.

7. Seeks reassurance from commissioners and providers on how family members and advocates are involved at and beyond an individual's transition between services and/or settings.

8. Seeks reassurance from commissioning and provider organisations on supervision practice, with a particular focus on frequency and the degree to which oversight of cases is challenging as well as supportive.

9. Engages with commissioners on maximising the strengths and addressing the challenges regarding commissioning arrangements for placements for people with complex physical health needs and learning disability.

10. Reviews practice regarding the provision of advocacy for adults with complex physical health needs and learning disability.

11. Seeks reassurance from statutory health and social care agencies regarding key working to ensure coordination in and review of complex cases involving physical and mental health needs and learning disability.

12. Promotes guidance on an adults at risk pathway and on the convening of multi-professional and multi-agency conferences on complex cases involving learning disabled adults with

physical and mental health needs, including the availability of specialist learning disability practitioners and legal practitioner advice that ensures that all options are considered, including referral to the Court of Protection.

13. Commissions a review of other cases involving transition to supported living, using the learning from this case.

14. Develops and promotes practice guidance on best practice regarding transition into and subsequent support of disabled people in supported living, using the learning from this case.