Bedford Borough
Safeguarding Children Board

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Child Patrick

Serious Case Review

Report for publication on 23rd May 2016

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1. Introduction

1.1 Reason for Review

This Serious Case Review (SCR) was commissioned by Bedford Borough Safeguarding Children Board (BBSCB) following the sad death of Patrick at the age of 17 years 4 months in Hospital. Patrick was hospitalised following a period of illness and a fall/collapse from his bed. Patrick had a rare genetic medical condition which manifested as learning disability, scoliosis and a heart condition.

1.1.1 The following information was brought to the SCR panel for consideration:

The Ambulance Crew who attended Patrick reported that Patrick was severely disabled, both mentally and physically, and that he had a full length spinal rod; they expressed concerns about the living conditions being neglectful, unsanitary and a fire hazard and had found it difficult to move around because of boxes everywhere. There was a bare flex hanging from the light fitting in Patrick's bedroom so he had no working light in the bedroom that he shared with his uncle James. Patrick lived with his maternal grandmother as his main carer and James who was Patrick's maternal grandmother's son who also had the same rare genetic medical condition. Patrick was dirty in appearance and had faeces under his fingernails; he had a significant rash to his groin area due to wearing a pad, possibly for lengthy period of time, and had a graze that might have been caused by contact with a mattress spring. The Ambulance Crew asked Patrick's maternal grandmother to dress Patrick and it appeared she was becoming aggressive towards Patrick.

1.1.2 There was found to be no care package in place and there had been no Children's Services involvement with Patrick for many years. The last direct contact in respect of Patrick was in 2005.

1.1.3 James was known to Adult Services who had concerns regarding the home circumstances. James attended a day centre and frequently presented as dirty and unkempt; as a result he was showered at the centre due to the level of concern regarding hygiene. There had been a number of discussions with the Safeguarding Vulnerable Adult (SOVA) team regarding James and a decision was taken to continue with a care management approach and not formal safeguarding. Adult Services reported it was not known to them that a child or young person was in the household. They became aware of Patrick's presence in the house in July 2014. Reports from Adult Services indicated conditions suggestive of hoarding as well as very poor hygiene in the family home.

1.1.4 At the same time the School that Patrick attended, also had some concerns regarding neglect; these concerns included unclean presentation and Patrick being given food in his packed lunch that was on one occasion mouldy or that he didn't like. When Patrick was weighed in Hospital during his final admission, he was 6 stone 11 pounds (some of this was considered to be due to oedema[1] he was noted to have). He was reported to have weighed a stone less than this when weighed in School 5 months previously. Patrick had presented unkempt at School with an offensive odour. School held concerns that, following spinal surgery, Patrick's protective dressing was not kept clean post operatively; there were no discussions or referrals to Children's Services from School until September 2014 when additional concerns were raised.

[1] *Oedema* is the medical term for fluid retention in the body.

1.1.5 In July 2014, Adult Services noted the home conditions were poor and that Patrick was residing in the family home. They referred him for transition support as he was age 17; no safeguarding referral was made to Children's Services however there was a discussion between the Adult Learning Disability Team (ALDT) and Children with Disabilities Team (CWD).

1.2 Methodology

1.2.1 In recognition of the health and safeguarding issues for Patrick, the BBSCB Independent Chair, Jenny Myers, appointed two experienced Overview Reviewers, one from a health background (Nicki Walker-Hall) and one from a social work background (Sue Gregory).

1.2.2 The methodology used was underpinned by the requirements contained within Working Together 2013[2] which states a review will:

- Recognise the complex circumstances in which professionals work together to safeguard children;
- Seek to understand precisely who did what and the underlying reasons that led individuals and organisations to act as they did;
- Seek to understand practice from the viewpoint of the individuals and organisations involved at the time rather than using hindsight;
- Be transparent about the way data is collected and analysed; and
- Make use of relevant research and case evidence to inform the findings.

NB: This methodology meets the requirements of Working Together (2015) which came into force during the period of this review.

1.3 The Serious Case Review Process

1.3.1 The BBSCB brought together a panel of Senior Managers to oversee the review. The membership of the Panel and terms of reference are also contained within the project plan see appendix 1.

1.3.2 A chronology was developed based on existing records, policies and procedures were used to shed further light on practice. Two practitioners' events were held to explore issues relating to assessments and transitions. In addition some key individuals and groups, directly involved in Patrick's care, were spoken to in order to give context and insight into contributory factors. A further event was held to ensure the analysis and conclusions of the report were reflective of the experiences of the professionals involved. The terms of reference provided a framework for analysis of all the information gathered.

1.3.3 The panel met on five occasions to review the information, develop an analysis and to consider the draft report provided by the Overview Reviewers. The government has introduced arrangements for the publication[3] in full of Overview Reports from Serious Case Reviews. This report has been written in the anticipation that it will be published. Consequently the information in the report:

- Is appropriately anonymised;

[2] Working together to safeguard children and their families (2013)
[3] See Working Together 2013

- Takes reasonable precautions not to disclose the identity of the children or family;
- Protects the right to an appropriate degree of privacy, of family members;
- Avoids the possibility of heightening any risk of harm to these children or others.

All names have been changed within the report to protect the anonymity of all involved parties.

1.4 Period Covered by the Review

1.4.1 The review covers a period of time from June 2012 up to the date of Patrick's death in November 2014. This time frame has been reviewed in detail but where relevant, information relating to the terms of reference outside of this time frame, has been included.

1.5 The Family

Identifying names/ initials	Relationship to Patrick	Age at time of commencement of the review
	Maternal grandfather	Deceased 2009
	Maternal grandmother (primary carer)	62
	Mother	36
Rosie	Half sister	6
Olivia	Half sister	5
James	Uncle	28

1.6 Family Involvement in the review process

1.6.1 Patrick's mother and maternal grandmother both agreed to be interviewed as part of the review process. The interview was helpfully facilitated by the current allocated Social Worker for James and undertaken with both Overview Reviewers present. Patrick's mother's and maternal grandmother's views are incorporated and appear throughout the report. A decision was made by the panel not to invite the wider family to contribute to the review.

1.6.2 Patrick's father has had no involvement in Patrick's life and therefore has not been spoken to as part of this review.

1.7 Rare genetic condition

1.7.1 Patrick had a rare genetic condition that affects approximately 1:40000 to 1:50000. This condition affects many parts of the body. The signs and symptoms are usually more severe in males than in females, although the features of this disorder range from very mild to severe in affected women. Males with this condition typically have severe to profound intellectual disability and delayed development. Beginning in childhood or adolescence, some people with this condition experience brief episodes of collapse when excited or startled by a loud noise. These attacks are called stimulus-induced drop episodes (SIDEs).

1.7.2 Most affected males and some affected females have distinctive facial features including a prominent forehead, widely spaced and downward-slanting eyes, a short

nose with a wide tip, and a wide mouth with full lips. These features become more pronounced with age. Soft hands with short, tapered fingers are also characteristic of this condition. Additional features of this condition include short stature, an unusually small head (microcephaly), and progressive abnormal curvature of the spine (kyphoscoliosis), other skeletal abnormalities and cardiac abnormalities.

1.8 Limitations

1.8.1 There were a number of limitations to the review. The SCR panel were not in receipt of accurate information at the beginning of this process and believed the issues in the case were ones of assessment and transitions so no Integrated Management Reviews (IMRs) or in-depth agency reports were requested.

1.8.2 The Overview Reviewers were unable to interview a number of the acute Hospital staff due to time pressures; in some cases, these staff had left the organisation. The Overview Reviewers were confident they had sufficient information to identify the lessons to be learnt except in regard to the impact of a failure to follow the Child Death Overview Process.

1.8.3 The Overview Reviewers requested a discussion with the Coroner in an attempt to understand the impact of this on this case; this was declined.

1.9 Local context and service provision for disabled children and young people

1.9.1 The children with disabilities (CWD) team assess the needs of children with a recognised disability or complex additional health needs. They work closely with local Schools for children with Special Educational Needs and get most of their referrals from this source.

1.9.2 The children referred to the CWD team generally have extremely complex needs and Social Workers are required to ensure that the assessments they complete are detailed and make recommendations which are evidence based; designed to meet the needs of those children and their carers' and focussed on supporting the carer to continue to be able to care for the child. The CWD team also has cases involving Child Protection Plans and children who are Looked After.

1.9.3 Cases that are held within the CWD team are often cases that will remain with the team for a long time, possibly through to their transition to Adult Services so the team only has a limited ability to manage the volume of cases requiring allocation.

1.9.4 The School where Patrick attended is a day School for children and young people between the ages of 2 to 19 years. Their pupils present a range of complex needs, which include;

- Severe Learning Difficulties (SLD)
- Autistic Spectrum Conditions (ASC)
- Profound and Multiple Learning Difficulties (PMLD)
- Multi-Sensory Impairment (MSI)

1.9.5 They became a Specialist School in Communication and Interaction in September 2009 and acquired Academy status with effect from 1st September 2011. The latest Ofsted inspection of the School in September 2014 judged them to be an outstanding School.

1.9.6 The School is organised into a Primary Department (2-11 years) including Early Years Foundation Stage and a Secondary Department (11-19 years) including a Post-16 Provision. The departments are led by members of the School Leadership Team. Class groups are arranged by age, physical and sensory needs and social communication compatibility. Class sizes reflect the needs of the pupils but are much smaller than those at most mainstream Schools.

2. Summary of case

2.1.1 Patrick, a white British boy, was 17 years old when he died in Hospital. Patrick was in the care of his maternal grandmother prior to his admission. Patrick had been placed in the care of his maternal grandmother and his maternal grandfather from the age of 3 years old. His maternal grandmother was also caring for her own disabled son (James). Both James and Patrick had a rare genetic condition which affected them physically and intellectually; James has a more severe form of the syndrome. Patrick was affected intellectually and physically, Patrick was short in stature[4] and had a scoliosis[5]. During spinal surgery for his scoliosis Patrick was found to have a heart condition (moderate mitral valve regurgitation[6] and left ventricular dysfunction[7]). Patrick's cardiac condition was managed by a specialist centre outside of Bedfordshire and at his last review by the cardiologist in April 2013 Patrick was asymptomatic[8], stable and it was thought he was likely to remain so for many years.

2.1.2 Patrick's maternal grandmother and mother were both carriers of the gene for the rare genetic condition and were affected by the syndrome in as much as, they displayed the distinctive facial features as seen in persons affected by this syndrome. Patrick's maternal grandmother's and mother's intellectual abilities were not assessed as no-one highlighted a concern about their intellectual abilities.

2.1.3 Patrick had been known to Children's Services as a young child. Issues of neglect whilst in the care of his mother led to a period of Children's Services involvement and registration on the Child Protection Register under the category of neglect. This in turn led to him being placed under a Residence Order with his maternal grandparents, in 2001.

2.1.4 Short breaks with foster carers commenced while Patrick was subject to a Child Protection Plan and were taken up by the family until 2005 when Patrick's foster carers retired. An offer of new carers was declined by the maternal grandparents and respite care halted. Patrick's maternal grandmother was initially supported by her husband until his death in 2009. Following cessation of respite care, there was no further involvement with Children's Services in respect of Patrick.

2.1.5 Patrick's mother gave birth to Patrick's half-sisters Rosie in 2008 and Olivia in 2009.

2.1.6 In April 2011 Olivia and Rosie were temporarily placed with maternal grandmother, due to their mother's neglectful parenting. At this time School raised concerns that Patrick has been infested with head lice for many months; Patrick's maternal grandmother was contacted by the School but no contact was made with any other professional.

[4] height below typical
[5] Scoliosis is the abnormal twisting and curvature of the spine
[6] one of the valves in the heart is letting blood leak backward
[7] left ventricle of the heart was functionally impaired
[8] there are no symptoms

2.1.7 In June 2012 Patrick attended a pre-operation planning meeting with maternal grandmother for Patrick prior to his spinal fusion. Maternal grandmother declined a hospital bed post operatively and social care support, a home assessment was planned but not completed. The family raised concerns regarding maternal grandmother's ability to care for both disabled young people within her care.

2.1.8 During the period under review the day centre attended by James had concerns regarding his hygiene which led them to a contact the Safeguarding Vulnerable Adults team (SOVA) on one occasion. Maternal grandmother was offered a number of Carers Assessments in respect of James which were either declined or when completed, the services offered were declined and a Living Skills Assessment was completed with James.

2.1.9 In January 2013 Patrick had his spinal operation, post-surgery the Community Nurse visited the home on one occasion offering wound care.

2.1.10 Patrick's general attendance at School was good, and despite his condition he had little contact with his GP. In his final weeks, before admission to Hospital, School had been alerted to concerns regarding Patrick's home conditions. Patrick was absent from School in September 2014, Patrick's maternal grandmother when contacted said she believed he had a cold, and initially tried to treat him with over the counter medication returning him to School after a week. School raised concerns on the 19th September 2014 that Patrick remained unwell and was short of breath when walking. He was pale and his lips were noted to become blue on exertion requiring rest to recover so, he was returned home.

2.1.11 On the advice of the School Special Needs Nurse Patrick's maternal grandmother took him to see the GP on 24th September. Patrick was prescribed antibiotics and in recognition of his cardiac condition, arrangements were made for him to have an Electrocardiogram (ECG), to assess the functioning of his heart. Patrick's maternal grandmother later advised the School Patrick wouldn't return to School until after his ECG on 24th October 2014. Up until this time Patrick had been assessed by the Community Paediatricians as a well disabled child with no requirement for regular paediatric review.

2.1.12 On the 14th October 2014 Patrick's maternal grandmother called an Ambulance, she reported Patrick had fallen from his bed following her request that he get up. The Ambulance Crew expressed concerns about the living conditions being neglectful, unsanitary and a fire hazard and had found it difficult to move around because of obstacles in the form of boxes everywhere. There was a bare flex hanging from the light fitting in Patrick's bedroom so he had no working light in the bedroom that he shared with his uncle (James). Patrick was dirty in appearance and had faeces under his fingernails; he had a significant rash to his groin area due to wearing a pad, possibly for a lengthy period of time, and had a graze and bruise to his left arm that might have been caused by contact with a mattress spring. The Ambulance Crew asked Patrick's maternal grandmother to dress Patrick and it appeared to them she was becoming aggressive towards Patrick.

2.1.13 Patrick was admitted to Hospital initially for assessment following his fall and for bruising which was noted on various parts of his body. Shortly after admission it was identified that Patrick's cardiac condition had deteriorated and, on the 16th October he was admitted to critical care, a diagnosis of multiple organ failure was made. Patrick was transferred to the paediatric ward for end of life care and died in November.

3. Patrick

3.1 Patrick's maternal grandmother and mother described Patrick as 'funny' and a 'womaniser'. Patrick was perceived by professionals to be a happy young man who used very positive language when talking about his maternal grandmother and James; he was able to talk about maternal grandfather and reminisce. Patrick's maternal grandmother, mother and School all indicated that Patrick made and maintained friendships. He was noted to know the names of all his class mates and talked about his School friends at home. Patrick was described as having limited formal means of communication but made good use of aids and was very communicative through facial expressions and gestures; he was also able to express his emotions. Patrick had made significant progress physically following his spinal surgery and was described by School as 'a swimming champion' and also enjoyed cycling; a newly acquired skill.

4. Relevance to wider context of safeguarding disabled children and young people

4.1.1 The death of Patrick was a shock to all the professionals involved in his life. Patrick was perceived to be a happy, relatively healthy, young man who had made significant progress physically following his spinal surgery and was transitioning well from childhood to adulthood. Whilst the progression to Patrick's death is unusual, there are many factors identified in this case which mirror the findings in other Serious Case Reviews of disabled children and young people.

4.1.2 Safeguarding concerns for disabled children and young people can arise in a number of ways. In this case, any concerns professionals had before his final weeks were intermittent and were not recognised as safeguarding concerns. There is a need for staff working with disabled children and young people to be ever vigilant and open to the concept that they may be suffering harm either through omission or through wilful neglect.

4.1.3 In this case there is no suggestion of wilful neglect but there is a suggestion that some of his care needs were not being met by his carers and, further, these needs were not identified by professionals as him requiring additional support and services.

4.1.4 The findings from this review require the BBSCB to assure itself that the lack of recognition of Patrick as a Child in Need is not reflective of the general response by professionals across Bedford Borough to other disabled children and young people.

4.1.5 We learned that disabled children and young people who have significant active health conditions were not seen regularly by Paediatricians who, in turn, were reliant on parents and carers to recognise and respond to changes within the child or young person's health. This was a reactive approach to their health needs and, without change to this practice; it is possible that this situation could be repeated in other cases.

4.1.6 In this case the role of the GP is unclear. GP's are usually the ones that 'hold the ring', providing centralized care. The impact of Patrick having a Community Paediatrician who was his clinician and specialist care for his cardiac condition seems to have blurred the GP's role. This resulted in no medical professional taking a lead to ensure a coordinated medical care plan was compiled and implemented.

4.1.7 This review suggests that disabled children and young people in Bedford Borough may not be afforded the level of scrutiny and investigation that their conditions require when indicators of abuse and neglect are present. There appears to be a greater acceptance by professionals of unacceptable levels of care and as a result risks of harm may not be identified or assessed. This mirrors the findings in the Local Ombudsman report (2009).[9]

4.1.8 The Overview Reviewers found there was a tendency to focus on "the concern of the moment" rather than seeing the whole picture. There was an inadequate use of chronologies which, had they been used, may have aided in an earlier identification of problems in this case.

4.1.9 Professionals missed opportunities to undertake comprehensive assessments, to link services, to facilitate a wider appreciation of individual family member's needs and, in turn, to inform multi-agency discussion and identify the need for early help or escalate to the level of statutory intervention.

5.1 Appraisal of Practice

5.1.1 Patrick, the subject of this review, was not expected to die, by those professionals with on-going direct involvement in his care, prior to his admission to Hospital. Patrick's death could not have been predicted by the professionals who had been working with the family.

5.1.2 There is no certainty that any of the findings below would have made any difference to the outcome in this case. Prior to September 2014 Patrick had been well and making progress physically.

5.1.3 This chapter provides the findings from this Serious Case Review along with issues for consideration by the BBSCB.

5.1.4 BBSCB has written a separate document, describing the actions that are planned to strengthen practice in response to the findings and issues for consideration from this Serious Case Review.

5.1.5 The findings are split into findings relating to:

- Assessment in disabled children and young people
- Lead professional role within health
- The use of terminology
- Safeguarding processes
- Assessments
- Transition processes
- The voice of the child

5.2 The systems in place within Bedford Borough did not ensure that all disabled children and young people were having their needs assessed or reassessed or receiving services designed to meet their individual needs throughout their childhoods.

[9] Local Government Ombudsman (2009) Six lives: the provision of public services to people with learning disabilities

5.2.1 This finding addresses the reason why some disabled children or young people fall through the gap of being provided with appropriate service provision.

5.2.2 Disabled children and young people are amongst the most vulnerable in society and as a disabled young person there were opportunities for Patrick to be considered under Section 17 of the Children Act[10] as a Child in Need of support and services; this was particularly so at points when concerns arose.

5.2.3 In this case Patrick was not receiving any services from the CWD team during the period under review. This was initially as a result of their closure of the case in 2005 following the ending of short break respite care. Subsequently there was no system in place to prompt this service to review his case and he became invisible to the service. As a result Patrick's maternal grandmother was not offered a Carers Assessment in respect of Patrick and no assessments of Patrick's needs were made despite changes in his needs.

5.2.4 In order for Patrick to receive a service from the Local Authority professionals involved from other agencies would have to refer their concerns either directly to the CWD team for support and services or through the MASH (Multi Agency Safeguarding Hub) for child protection concerns. As those agencies did not recognise the threshold had been met to make a referral for either support and services or child protection until September 2014, so Patrick and his maternal grandmother were left unsupported in the home environment. Below are some examples.

5.2.5 Patrick was using aids in School to assist his independence, for instance adaptations to taps which enabled him to have an increased level of ability; the same aids were not available to him in the home. Patrick had an operation during the timeframe which had some positive benefits to his mobility but also made some tasks more difficult, for instance getting in and out of his bed and the bath. Patrick and his maternal grandmother were 'making do' within the home, for example using an upturned tub to stand on to get into bed and washing in a bowl as he couldn't get into the bath. A proposed home occupational therapy assessment did not take place and a system to ensure these assessments are completed was not evident.

5.2.6 It would have been good practice for professionals to alert Children's Social Care through the MASH at points when Patrick's hygiene needs were not being met, when his mobility changed as a result of his surgery and when family members were expressing concerns about the amount of responsibility maternal grandmother had caring for Patrick and James and the unsanitary state of the house. Maternal grandmother gave a consistent message that she could manage which impacted on professional's actions.

5.2.7 Miller & Brown[11] note the pressure to work in partnership with parents and carers *'....can inadvertently lead to an overly parent-focused approach in which the importance of consulting with the child is diminished and there is an over-reliance on the parent/ carer's account of a child's behaviours and needs. Serious care reviews have often identified a reluctance to challenge professionals and parents' explanations to concerns for the wellbeing of a child. This risk of this happening for disabled children is likely to be greater. Professionals may feel the parent/carer is doing their best and continue to seek to work 'in partnership', in consequence compromising child protection standards.'*

[10] Children Act. 1989

[11] Miller D & Brown J (2014) 'We have the right to be safe' Protecting disabled children from abuse' NSPCC

5.2.8 There is currently no system in place to monitor involvement of those families who are not requiring support and services at the current time, or offer them Carers Assessments (see finding 5) as per the Care Act 2014. As a result there is potential for this situation to arise for a significant number of disabled children and young people across Bedford Borough.

Issues for consideration by the BBSCB

- What role does the BBSCB take in ensuring the systems around identifying and assessing disabled children's and young people's needs are robust?
- Are professionals working with disabled children and young people in Bedford Borough adopting an overly parent-focussed approach?
- Is safeguarding training equipping staff with the skills to be able to identify indicators of abuse and neglect and take appropriate action?
- Are there other disabled children and young people within Bedford Borough who are not having their individual needs assessed?
- Are there other disabled children and young people within Bedford Borough struggling because they are not in receipt of the aids that would increase their quality of life and independence?

5.3 There was no system to identify the lead professional within health for a disabled child or young person which meant it was unclear who was fulfilling the role for Patrick; as a result his cardiac condition was not being monitored in between annual specialist appointments.

5.3.1 This finding addresses the reason why some disabled children and young people fall through the gap of being provided with appropriate health provision.

5.3.2 In this case Patrick was known to his GP, two specialist Hospitals, a Specialist School Nurse and Community Paediatricians; he had no involvement with Paediatricians from the local Hospital. It is usual for the GP to hold all the information regarding the health of all their patients and that is the case here. Confusion arose within this case as it was open to the Community Paediatricians and both they and the GP were in receipt of information from the Cardiologist at the specialist Hospital, the Specialist School Nurse and the local Hospital were not. Understanding the local system and their roles within that was crucial to all parties.

5.3.3 GP's are dependent on families bringing their children for review, usually at times of illness. Patrick was generally very well so had very limited contact with the GP unlike many disabled children and young people. It would seem a reasonable assumption to the GP that the Community Paediatricians would be monitoring Patrick regularly including his cardiac condition. However the system of only regularly reviewing those disabled children and young people with underlying medical conditions that required medication meant no one locally was reviewing his cardiac condition between specialist appointments. This system meant the Community Paediatricians were over reliant on both the Specialist School Nurse (who had no knowledge Patrick had a cardiac condition) and the family to contact them if they were concerned. This system has recently changed.

5.3.4 This lack of lead professional had a wider impact as it meant no one was ensuring all health staff were cognisant of Patrick's health needs nor was anyone providing maternal grandmother with information as to what symptoms Patrick might develop which would require urgent medical attention.

5.3.5 If there had been a lead professional they should have communicated with the wider health community e.g. Specialist School Nurse on receipt of clinic letters and the local Hospital at points of admission.

Issues for consideration by the BBSCB

- Does the care pathway for disabled children and young people with long term conditions respond to not only their health needs but the information required by other health professionals and carers?
- Does the pathway ensure information known in the community is made available to the acute Hospital following admission and vice versa?

5.4 The use of terminology across and between agencies was confused as was the use of language; this was affecting practice.

5.4.1 This finding addresses the confusion created by using terminology that has different meaning for different agencies involved and is significant in deciding which, if any, systems or processes need to be followed.

5.4.2 In this case there was confusion regarding the terminology used between agencies. This was in respect to two specific terms.

5.4.3 Within health the term 'expected death' versus 'unexpected death' caused confusion for Police colleagues. In health an unexpected death is defined by the World Health Organisation as an individual who dies from natural diseases within 24 hours of symptoms appearing. An expected death is one which occurs after the person has been unwell in Hospital for over 24 hours. When there is an unexpected death the Hospital are obliged to notify the Coroner and an autopsy will always be held to establish the cause of death. If the person has been in hospital over 24 hours and the cause of death has been clearly established a decision may be made that there is no value in doing an autopsy.

5.4.4 For the Police the terminology used suggested that health professionals had expected Patrick to die as a result of his health condition and therefore there were no concerns that there were any contributory factors to his death they needed to investigate. What we learned was Patrick was not expected to die by any professional until after his admission in October. He was being seen annually for an underlying heart condition that had caused no concerns and had required no treatment and was not expected to require treatment until he was over 18.

5.4.5 As a result of the confusion and delay in progressing the MASH referrals (see Finding 4) coupled with the confusion around terminology, Police investigation was not considered necessary and no autopsy or Coroners inquiry conducted.

5.4.6 There was confusion around the term wilful and non-wilful neglect and this influenced police decision making. The term wilful is significant for the Police because if they have evidence any neglect was wilful they have a duty to pursue a criminal conviction; discussion regarding this was evident in the strategy meeting. The discussion however doesn't demonstrate full consideration of the need to investigate non-wilful neglect as part of safeguarding children protection procedures.

5.4.7 Ambulance staff made a good referral, using descriptive language that conjures a picture of the environment Patrick was living in, the School also made a referral that

conjured up a similar picture of the environment (see finding 4). However when the home environment is described within Carers Assessments or within meetings the language used dilutes the level of concern for the reader. An example of this would be the Ambulance Crew described the home as 'unsanitary with a foul smell and a fire hazard' whilst the minutes of the S47 Strategy meeting state 'poor home conditions'.

5.4.8 This situation is relatively rare and therefore it has not been possible to establish how likely it is this may happen again. The Police have confirmed the term expected and unexpected did cause confusion and as the result of the confusion has had an impact on investigation by the Police and possibly the Coroner this is significant and requires addressing.

Issues for consideration by the BBSCB

- Is the language being used across Bedford Borough leading to safeguarding concerns being under assessed?
- Is the terminology stopping deaths that occur after 24 hours of admission to Hospital, being robustly investigated where there are concerns around abuse and/or neglect?
- Are the Police fulfilling the requirement to investigate neglect concerns to safeguard the welfare of children and young people regardless of whether the neglect is wilful or not?

5.5 Safeguarding Processes. The response to all referrals regarding the children/young people in this family into the MASH was not robust and the RAG rating too low. The response led to confusion within services, delays in assessment and limited scope for investigation.

5.5.1 This finding addresses the issues relating to the MASH and the response to safeguarding concerns raised by three agencies.

5.5.2 In this case there were three referrals into MASH in the weeks prior to Patrick's death all relating to concerns about neglect. The first concern was raised by Patrick's School and related to information received regarding hygiene in the family home. The information indicated the home was smelly, dirty and cluttered with flies flying around unwashed items. The MASH RAG rated the referral green and advised the School to seek agreement from maternal grandmother for a CAF referral; the School followed the advice given and arranged a Team Around the Child (TAC). It appears there was no recognition that Patrick was disabled and therefore already a Child in Need and no care package was in place. There was no request to speak to the person who had been into the home, nor consideration that a visit to assess the family home would be useful.

5.5.3 The second referral made by the Ambulance crew again expressed concerns at the living conditions. In addition Patrick presented as unclean, with a severe angry rash in his groin area and faeces under his fingernails. In addition there were physical injuries thought to be related to his fall however Patrick's maternal grandmother was noted to be unnecessarily aggressive to Patrick when dressing him; this referral was again RAG rated green with no clear response.

5.5.4 This referral should have been RAG rated red and Section 47 enquiries commenced which would have escalated the case above the level of a CAF and stopped the TAC

meeting being held. Neglect is a form of abuse that practitioners find challenging to address. A recent paper by *Brandon et al* notes the fact that:
'...numerous Serious Case Reviews show, professionals, may individually have concerns about a neglected child, but too frequently these concerns do not trigger effective action.'[12]

5.5.5 The third referral from the Hospital was in response to the lack of progression of the previous referral and made in a bid to involve the CWD team. Had Section 47 enquiries commenced there should have been no need for this referral. The CWD team indicated they were aware of the previous referral but were unable to record or process work on the system as the MASH hadn't passed it on or put it on the system; the CWD team decided to wait until it was received. The delay in processing the MASH referral continued and in November 2014 a discussion took place between the Hospital's Named Nurse Child Protection and the MASH. The MASH indicated that they had not received the third referral thus it was resent.

5.5.6 The MASH is the front door into services for all children and young people in Bedford Borough. At this time the MASH itself was on the BBSCB risk register, so issues were known. The MASH had just undergone an independent review which identified that the service was not operating as a MASH should, but as a Single Agency Safeguarding Hub; in effect another layer of the Children's Services duty system. It was known there were serious delays for all cases that had been RAG rated green.

5.5.7 A RAG rating of red would have been appropriate to all the referrals and as a result Section 47 enquiries should have been instigated and a full joint investigation with the Police. Patrick received protection through hospitalisation not through application of local policies and procedures.

5.5.8 The response by the MASH led to confusion, delay, lack of assessment and impeded the ability of the Police to investigate.

5.5.9 The review of the MASH found no issues with the RAG rating, however that is not the case for Patrick where on all occasions the Overview Reviewers believe the referrals warranted a more robust response and a higher RAG rating than was awarded. Disabled children and young people are known statistically to be more vulnerable to abuse and/or neglect by their carer's, albeit this is not reflected in terms of children or young people subject to Child Protection Plans. *Miller & Brown* (2014)[13] note the significant barriers in child protection processes for disabled children or young people which were all present in this case: 'recurring themes include failure to recognise abuse or apply appropriate thresholds; lack of holistic assessment; lack of communication with the child or young person and maintaining a focus on their needs; and, despite improvements, a continuing lack of effective multi-agency working (Ofsted 2009, 2012; *Brandon et al. 2012; Taylor et al. 2014*). In England Ofsted (2012) found in particular that Children In Need work was not always well coordinated, with many plans lacking detail and focus on outcomes, and that this lack of rigour increased the likelihood of child protection concerns not being identified early enough. The report also found delays in identifying thresholds for child protection when concerns were less clear-cut, especially neglect.

5.5.10 Staff report there remain issues around thresholds however it hasn't been possible to clearly establish how wide spread the problem is.

[12] Brandon M, Glaser D, Maguire S et al (2014) *Missed opportunities: indicators of neglect - what is ignored, why and what can be done?* , London: Department for Education
[13] Miller D & Brown J (2014) 'We have the right to be safe' Protecting disabled children from abuse' NSPCC

5.5.11 A Section 47 Strategy meeting was held on the day Patrick died. It came to a number of conclusions the Overview Reviewers cannot reconcile:

- Patrick would not have been allowed to go home but James remained within the household
- The Adult Social Worker would be the lead professional for Patrick - this was not appropriate as Patrick was still a child
- That as this was not a case characterised by wilful neglect there was no role for the Police at that time. The case had not been thoroughly investigated or assessed when this decision was reached however the group were invited to come back to the Police if there were continued or additional concerns.

Issues for consideration by the BBSCB

- Is the threshold document being consistently applied and the system for RAG rating referrals robust?
- Is the IT recording system and the use of the system within the MASH affecting the progression of referrals?
- Are referrals pertaining to disabled children and young people being considered with 'Child in Need' in mind?
- Is multi-agency working effectively protecting disabled children/young people and disabled adults?
- Is there clarity between children/young people and adult safeguarding professionals and services when managing 16-18 year olds?

5.6 There was no system in place to ensure Carers Assessments were being offered to the carers of disabled children and young people and no connection between Adults' and Children's Services when carers were caring for an adult and a child or young person.

5.6.1 This finding relates to the issue of no Carers Assessments being offered in respect of Patrick and those completed in respect of James were done with no recognition of Patrick.

5.6.2 During the review period there were four occasions Carers Assessments in respect of James were noted as required, on three occasions they were offered, twice maternal grandmother declined the assessment and on one occasion it was completed however she declined the support assessed as required. The assessment did not clarify who the occupants of the house were and so did not identify Patrick's mother or Patrick as part of the household. As a result of this omission maternal grandmother's full care responsibilities were not recognised. On the fourth occasion instead of a Carers Assessment a Living Skills Assessment is completed for James and he agrees to have showers three times a week at his day centre. In order to complete the paper work a home visit is conducted where it is noted Patrick is also part of the household.

5.6.3 There were no Carers Assessments in respect of Patrick because there was no Children's Services involvement and no mechanism in place to trigger a Carers Assessment to be offered. The Care Act[14] and the Children and Families Act[15] now

[14] Care Act (2014)
[15] Children and Families Act (2014)

provide a clear strategic framework for Carers Assessments however under the Children Act[16], it has always been expected that an assessment of a child 'in need' under Section 17, including all disabled children and young people, will be 'holistic' and will take account of the needs of other family members. In addition Section 6 of the Carers and Disabled Children Act[17] indicates the Local Authority must provide information on the rights to a Carers Assessment.

5.6.4 It is clear Carers Assessment should have been offered in respect of Patrick, also the Carers Assessments completed in respect of James should have included the wider information regarding the family, in order a more accurate assessment of maternal grandmother's care responsibilities be made.

5.6.5 During the Carers Assessments in respect of James, James's mother (Patrick's maternal grandmother) indicated that she didn't need any support and is described by professionals as 'proud'. In her discussions with the Overview Reviewers she expressed a view that there were 'families worse off than them' and that 'they managed'. Professionals perceptions coupled with Patrick's maternal grandmother's stance influenced professional practice. It was clear to those completing the assessments that not all James's care needs were being met within the home, e.g. showering, and whilst alternate arrangements were made for James a lack of holistic assessment of the family meant the same interventions were not afforded to Patrick. At the point of rejection of support and services, an assessment of the impact of this on James needed to be made.

5.6.6 The conflict between a professional's view on acceptable standards of care and a carer's view is always difficult – in these situations a holistic view on a multi-agency basis is always helpful. Using tools designed to explore the impact of the carer's wishes on those in their care is essential. Staff did not consider the wider impact of Patrick's maternal grandmother's decisions on the care afforded to Patrick and James nor whether other assessments and interventions may be indicated or required. There was a lack of challenge of Patrick's maternal grandmother's decision making regarding support and a ready acceptance of her stance. It has been acknowledged by the Manager within Adult Services that the Carers Assessments were not of good quality and should have enquired as to who was living in the house. The Manager believes that the quality of Carers Assessments has improved.

5.6.7 This is a systemic issue suggesting many disabled children and young people's carers are not receiving their statutory offer of a Carers Assessment.

Issues for consideration by the BBSCB

- How are Carers Assessments being offered to parents and carers across Bedford Borough?
- How are all carers going to be identified?
- How can information pertaining to a carer who has both a child and a young person within their care going to be shared?
- How do Carers Assessments fit within the wider safeguarding system to trigger further assessment for both children and young people and adults to ensure their needs are being met?

[16] Children Act (1989)
[17] Carer and Disabled Children Act (2000)

- How can the BBSCB and Adult safeguarding Board (ASB) be assured that Carers Assessments are of sufficient quality to satisfy the Boards that they identify the carer, children, young people and adults care needs?
- Is the impact of refusal of support leading to further exploration the outcome?

5.7 Transitions. The systems and processes around transition within and between Children's and Adults' Services in Social Care and in Health were not robust nor consistently applied. The transitions protocol was insufficiently detailed to ensure it covered all disabled children and young people, including those not in receipt of support and services from the CWD team.

5.7.1 The transition process was thought by those involved to be compromised by the fact the case was not open to Children's Services. School were unclear regarding the need to notify the Adult Learning Disabilities Team (ALDT) of Patrick in year 9 and did not appreciate the full extent this would allow for further planning for Patrick's future. The School indicated that as Patrick was staying under the umbrella of the School until he was 19 they didn't recognise the need for transition until the summer prior to his death.

5.7.2 The Manager of the Adult Learning Disabilities Team indicated that the mistake of the past has been waiting for information to come to the team from Schools. She now sees SEND[18] was the key to implementing transition; the transition protocol is now under revision and a draft out for consultation.

5.7.3 The process within the Hospital had been aligned to other local Hospitals and meant all children and young people, including disabled children and young people, who are over 16 are admitted to adult wards unless they are receiving ongoing acute Paediatric care. Patrick was not under a Hospital Paediatrician thus was admitted to an adult ward under adult Physicians; this distressed him and was inappropriate based on his level of ability.

5.7.4 The result of this was the need to transfer him from an adult ward to a children's ward so his care needs could be met by appropriately trained Paediatric Nurses however he remained under the care of the adult Physicians. These Physicians have greater understanding of adult processes and thus there was confusion as they believed a Safeguarding Vulnerable Adult referral had been made. The Hospital's Named Nurse Child Protection had been notified of Patrick's admission and concerns and thus oversaw the safeguarding concerns however the Physicians did not question the appropriateness of a Safeguarding Adult referral as opposed to a Child Protection referral, were largely unaware of the progression of the safeguarding referrals and abdicated responsibility to the Named Nurse Child Protection.

5.7.5 No information was sought or available from the Community Paediatricians or GP; this together with a lack of information sharing from the tertiary Hospital meant that results from tests and recent consultations regarding Patrick's heart condition were not known to the treating Physicians.

5.7.6 The issues raised within this finding apply to all disabled children and young people who are not receiving support and services through the CWD team or who are not under the care of an acute Hospital.

[18] Special Educational Needs and Disability system

Issues for consideration by the BBSCB

- Is the proposed system within the transition protocol sufficiently robust to transition all disabled children and young people into appropriate Adult Services?
- Are systems within the local hospital taking sufficient account of disabled children and young people's so they are being cared for in appropriate settings by appropriately trained Nurses and Doctors?
- Are the rights of all disabled children and young people being met by services across Bedford Borough through the Children, School and Families Bill implemented from September 2014[19]?
- Do adult Physicians have sufficient understanding of Bedford Borough's Children and Adult protection procedures and their individual responsibilities to safeguard?

5.8 The voice of Patrick, James, maternal grandmother, and the professionals involved. The voices of Patrick and James were not sought or sufficiently heard by the professionals who had responsibilities for them, nor were their daily lived experiences known. It was essential that the professionals who were involved with Patrick and James were in a position to advise those who did not know them and that those who did not know them seek the professional's advice.

5.8.1 Whilst communication with Patrick and James would undoubtedly have been more complex due to their disabilities, they did have the ability to communicate. We established Patrick had limited formal means of communication but he made good use of aids and was very communicative through facial expressions and gestures; he was also able to express his emotions. James was able to offer yes and no answers to simple questions.

5.8.2 It is difficult to say what Patrick or James might have communicated had they been spoken to by professionals; their level of cognition was graded differently by different professionals. Some staff believed it was unlikely Patrick would have been able to indicate anything more than pain. This conflicting opinion of Patrick's level of ability has been difficult to navigate and suggests differences in professional's abilities to assess how able a disabled child or young person is.

5.8.3 School indicated Patrick used very positive language when talking about his maternal grandmother and James, and was able to talk about his maternal grandfather and reminisce.

5.8.4 It appears there would have been some opportunity to understand Patrick's daily lived experiences but this was not taken. Maternal grandmother and mother were able to give the Overview Reviewers an insight into a typical day in Patrick's life. Professionals within the practitioner's events were surprised by their description. School staff indicated that Patrick required frequent prompting to complete any task e.g. dressing however we learned from his maternal grandmother he was not only self-caring but also assisted James to get dressed.

5.8.5 It is not unusual for professionals to indicate they cannot include the voice of the child as the child has no speech however work by the National Children's Bureau[20] and the Save the Children project CHOOSE found that even those children with complex and multiple disabilities, can participate effectively and have a right to do so. The

[19] Transition for Young Adults with Learning Disabilities (2014) Bedford Borough Council
[20] Dickens, M (2011) Listening to young disabled children. National Children's Bureau

'Ask Us' project (led by the Children's Society) and 'Two-Way Street'[21] (led by Triangle and NSPCC) both found that disabled children and young people had strong views about the society they live in, how they are treated, the services they receive, their education, health and leisure.

5.8.6 Latterly the delay in progressing the Section 47 enquiries meant an opportunity to speak to Patrick when his condition briefly improved, as part of those enquiries, was missed. There appears to have been little consideration or attempt to speak to James about his lived experiences throughout the review period save for his Living Skills Assessment. In addition no one has considered Patrick and James' mental capacity which was not widely known to those completing assessments; certainly the MASH and SOVA had no understanding of their level of capacity, ability or comprehension and there is no evidence this was questioned.

Issues for consideration by the BBSCB

- Are all professionals working with disabled children and young people regularly exploring their lived experiences with them, their carers' and those with parental responsibility, particularly when concerns arise?
- Is the MASH exploring how a child or young person's disability affects their ability to communicate, in order to plan their inclusion in any assessment process?
- Are multi-agency forums paying attention to individual children and young people's SEND assessments and Education and Health Care[22] plans?

6. Conclusions

6.1.1 This review has robustly examined the multi-agency involvement leading up to the death of Patrick. His death was certainly unexpected by those who knew him best and this review has not been able to entirely establish the circumstances around Patrick's health in the two weeks that led up to the Hospital admission. What is known is there were already concerns about the home environment which were referred to MASH.

6.1.2 Patrick's maternal grandmother believed Patrick had a cold; it was initially treated with over the counter medication. On the advice of the Special Needs Nurse Patrick's maternal grandmother took Patrick to see his GP who commenced him on antibiotics and ordered a repeat ECG to further assess his known heart condition.

6.1.3 A week later Patrick's maternal grandmother felt it was time for Patrick to get up as he had been 'in bed long enough.' He fell or collapsed getting out of his bed and Patrick's maternal grandmother called an Ambulance to assist her to get him up. It was clear to the Ambulance Crew there was neglect in the home, whether this contributed to Patrick's death we cannot know. A referral was made to MASH.

6.1.4 Patrick was initially admitted for observation because of the safeguarding concerns but was found to be dehydrated. Patrick's cardiac condition was found to be symptomatic and within 48 hours of admission he required transfer to critical care, in addition he was noted to have abnormal blood clotting and organ failure. After initial improvements it became clear Patrick was not going to recover and received 'end of life' care. A further referral was made to MASH by the Hospital.

[21] Marchant, R and Gordon, R (2001) Two-Way Street: Communicating with disabled children. NSPCC

[22] Transition for Young Adults with Learning Disabilities AS816-13 (Bedford Borough Council)

6.1.5 Issues within MASH at the time led to a three week delay in S47 enquiries being instigated and the Police becoming involved. The potential for assessing and gathering evidence was lost.

6.1.6 When Patrick subsequently passed away his death was treated as an expected death because he did not die within 24 hours of admission. His death however, followed an unexpected collapse and therefore the Child Death Overview Processes and Procedures should have been followed within the Hospital, an investigation mounted and the Coroner furnished with all the information from the investigation and the S47 enquiries.

6.1.7 Patrick's death during the strategy meeting appears to have halted the decision to make enquiries under S47 of the Children Act and is reflected in the minutes of the meeting. This decision should have been carried through into the child death process and to conclusion and not halted as a result of his death. The Adult Learning Disability Team were working with the family in respect of James, however having deemed the home environment unsuitable for Patrick to return to in the event of discharge, a decision should have been made to carry out a full investigation under safeguarding adults' procedures (now Section 42 Care Act) and give further consideration to the level of risk posed to James within the home environment. Following the strategy meeting the level of risk to James was managed through the systems already in place within the Adult Learning Disability Service.

6.1.8 What has emerged is a concerning picture of lack of recognition or response to indicators of abuse and neglect, lack of information sharing and referrals leading to a lack of assessment and the near invisibility of Patrick to a number of key services which were well placed to support him. The failure to fully explore both Patrick's and James's care needs and ensure Patrick's maternal grandmother had the capacity and skills to care for both dependents has, at times, left Patrick and James' basic needs (as defined by Maslow's hierarchy of needs), unmet.

6.1.9 Procedures, processes and systems in place to ensure disabled children and young people are safe and reach their potential in Bedford Borough were not always followed. Systems around transition for Learning Disabled Adolescents did not work effectively.

6.1.10 Patrick clearly enjoyed, developed and progressed within School; he developed significant skills and friendships. He was noted to be happy to go to School but also happy to go home. What is particularly sad is that no professional working with Patrick was aware of what Patrick's daily lived experience away from School was. Staff have shown a real desire to learn from this case and there is significant learning for all.

7. Additional Learning

7.1.1 There is additional learning that has fallen outside of the scope of this review which is still seen as significant and will be discussed in this section.

7.1.2 Patrick's maternal grandmother's ability to recognise signs and symptoms indicating a change in health and respond appropriately, are of concern in relation to James who remains in her care. A health facilitator is currently working with Patrick's maternal grandmother and a health action plan has been developed.

7.1.3 During this Serious Case Review (SCR) process there have been a number of challenges. The quality of the information initially shared with the Serious Case Review Panel which informed both the decision to conduct the SCR and the Terms of Reference was later found to be poor; this may be relevant for appropriate decision making on whether to conduct an SCR in other cases.

7.1.4 The quality of the chronology has been questioned throughout the process in terms of accuracy and the interpretation of recorded information in services. Chronologies need to be devised and shared with staff before collating the integrated chronology.

7.1.5 There have been difficulties across the practitioner's events as many of those who attended the two initial practitioner's events were not present at the final event to check accuracy and make comment. New practitioners were present who required the Overview Reviewers to revisit information already checked which impacted on time. The third event should only have been open to those present at the proceeding practitioners events.

What will the BBSCB do in response to this?

The BBSCB has prepared a response which describes the actions that are planned to strengthen practice in response to the findings and recommendations of this Serious Case Review below.

Appendix 1

Case review 2015: Patrick project plan

1. Decision to hold serious case review (SCR)/ or case review
The case was discussed on the 9th December 2014 at the Learning and Improvement Standing Group. The decision was made that the case met the criteria for a serious case review.

2. Family members

Identifying names/ initials	Relationship to Patrick	Age when the review commenced
	Maternal grandfather	Deceased 2009
	Maternal grandmother (primary carer)	62
	Mother	36
Rosie	Half sister	6
Olivia	Half sister	5
James	Uncle	28

2. Background
Patrick was recently admitted to Hospital following a blue light call by the Ambulance Service to his home. He was in Critical Care and the prognosis was poor. He was considered for pallative care and he fluctuated from end of life being anticpated as imminient to pallative status since he was admitted to hospital.

Patrick ordinarily resided with his maternal grandmother who was granted a Residence Order when Patrick was 2 years old. She was widowed several years ago. Patrick shared a bedroom with his 29 year old uncle James who also has the same medical diagnosis.. Like his uncle, Patrick had also undergone surigal procedure to place a rod in siti to the spinal column due to curvature of the spine, which is usually associated with this progressive condition. Patrick's two younger half-siblings are in the care of Bedford Borough Council and have quarterly supervised contact with Patrick.

Patrick's mother has returned to live in the maternal grandmothers home.

The Ambulance Service crew reported that Patrick is severely disabled, both mentally and physically, and that he has a full length spinal rod. He had fallen out of bed and was non weight bearing (drop falls are a possible feature of this condition.

Concerns were expressed by the Ambulance Crew about the living conditions being neglectful, unsanitary and a fire hazard. The Ambulance Crew found if difficult to move around because of boxes everywhere. There was a bare flex hanging from the light fitting in Patrick's bedroom (he had no working light in his bedroom that he shared with his uncle). Patrick was dirty in appearance and had faeces under his fingernails. He had a significant rash to his groin area due to wearing a pad, possibly for lengthy period of time and he had a graze that might have been caused by a mattress spring. The Ambulance Crew asked his maternal grandmother to dress Patrick and it appeared she was becoming aggressive towards him.

There was no care package in place and there had been no Children's Services involvement with Patrick for many years, although there was a contact (NFA) in 2013.

Patrick's uncle James is known to Adult Social Care who also had concerns re the home circumstances. James attends a day centre and frequently presents as dirty and unkempt. He is showered at the centre due to the level of concern regarding hygiene. There have been a number of low level discussions with the SOVA (Safeguarding of Vulnerable Adults) team in regards to James but no actions had been taken by the team. Adult Services have reported that it was not known by them that Patrick was in the household until July this year. Reports from Adult Services indicate hoarding conditions as well as very poor hygiene in the family home. James has presented at the day centre in damp clothes when the tumble dryer was broken (this was the explanation given for damp clothing to Adult Services). James has attended with clothes on the wrong way round and personal odour that indicates his needs are not adequately met. Adult Learning Disability Team (ALDT) were already working with the family and would pick up the safeguarding concerns.

School also had concerns re neglect, including Patrick's unclean presentation and being given insufficient food in his packed lunch. When Patrick's was weighed in Hospital recently, he was 6 stone 11 pounds. He is reported to have weighed a stone less that this when weighed in School 5 months ago. Patrick has presented as unkempt at School and offensive odours. School held concerns about Patrick's wound site not being clean or well managed post op (following spinal surgery 1 ½ years ago). However, there have been no referrals raised from the School.

From Hospital records health practitioners seem to have been concerned that maternal grandmother might not take Patrick to the GP thus felt a need to check if she had been and it appears she needed to encourage to take him for medical attention when he has been unwell recently. There has been no referral raised from Health to Children's Services.

In July 2014, it was noted by Adult Services that the home conditions were poor. It was at this junction that Adult Services noted Patrick as residing in the family home. They referred him for transition support as he was age 17 but no referral made to Children's Services.

4. Agencies/organisations involved:

- Bedford Borough Council Children's Services
- Bedford Borough Council Adults' Services
- South Essex Partnership Trust (SEPT) Services
- GP Practice
- School
- Hospitals

5. Period covered by the review

The period from June 2012 to Patrick's death November 2014 will be reviewed in detail and prior to this any relevant information to the terms of reference will be included.

6. Approach

- Participating agencies will all prepare and submit detailed chronologies
- Participating agencies will provide all relevant background information and documents
- Participating agencies will provide a context of the structures, processes and procedures during this timeframe
- Conversations with staff involved with Patrick and his family
- A case group may be convened

7. Lead reviewers (SCR Authors)

Nikki Walker-Hall and Sue Gregory have been commissioned to;

- Chair the SCR Group meetings,

- Undertake conversations with staff,
- Write the Overview report,
- Report back to the professionals involved in the case the learning
- Present the case to the BBSCB Strategic Board in December 2015.

8. SCR Group

The membership of the SCR Panel came from the following agencies;

- Bedford Borough Council Children's Services
- Bedford Borough Council Adults' Services
- South Essex Partnership Trust (SEPT) Services
- Bedford Hospital
- Bedfordshire Police
- Bedfordshire Clinical Commissioning Group

9. Practitioner Review Group

Practitioner Review Group will be convened with those who worked with Patrick and his family in the tiemscales identified above. Meetings will be held with these practitioners and chaired by the SCR Authors. There may also be a need for the SCR Authors to hold individual conversations with some of the practitioners involved.

10. Terms of reference

- What can this SCR tell us about how well children and young people with complex disabilities are safeguarded and if agencies work together effectively in the transition processes between children's and adults' services
- Why Patrick appeared to have slipped through the net?
- Did anyone challenge when maternal grandmother refused help?
- Concern regarding Patrick's weight/health re operation, his weight was very low?
- Did anyone assess/consider whether Patrick's faltering weight was due to his condition or neglect?
- How often and by whom was Patrick assessed/monitored by Health services?
- Did anyone assess/consider the health needs of the wider family members?
- Do we hear the voice of the child in any agency chronology – what was a normal day like for Patrick and James?
- How did maternal grandmother's refusal for help affect/impact on Patrick and James?
- Was the death of maternal grandfather significant? How did this impact on the maternal grandmother, Patrick and James's lives?
- What was the quality of assessments and information sharing for Patrick, James and Patrick's half-sisters?
- What is the role of the School and the Specialist Nurse?
- What safeguarding training was delivered to staff at School?
- What was the process with School in reporting and sharing concerns?
- What communication was there between the maternal grandmother and School?
- How effective was this communication and what impact did it have on Patrick?
- What was the quality of decision making for Patrick from all agencies?
- Do we fully understand neglect and how it manifests itself with children and young people with complex disabilities?
- Are Professionals reluctant to share safeguarding concerns about parents/carers who are caring for children/young people with complex needs?
- What was the quality of the response from MASH?
- Who was Patrick's father?
- Under what part of the Children Act were professionals working?
- Were the CIN procedures robust and followed appropriately?
- What was the statutory basis for working with this family?

- What was the legal status of Patrick?
- Who had PR for Patrick?
- How was PR managed between the maternal grandmother and Patrick's mother following the granting of the Residence Order?
- What was the role of Patrick's mother in his care?
- How is the involvement of CAMHS managed through transition from Children's to Adults' Services?

Factual matters to be established
All agencies involved with Patrick and his family to provide the Overview Authors with the following:
- Normal agency processes/procedures
- Agency thresholds
- Who was coordinating services for Patrick?
- What would normally happen in a case like this?

Evaluation of factors that shaped professional practice
- What contributory factors (at individual, team and organisational level) shaped professional practice and decision making by individual agencies and in the multi-agency network?
- How effectively did agencies and professionals work together across adult and children services?

Findings for the BBSCB
- What do the findings in relation to the care provided for Patrick tell the BBSCB and member agencies about the strengths and vulnerabilities of wider arrangements to safeguard and promote the wellbeing of children and young people?
- What steps should the BBSCB or member agencies consider taking in order to improve services for vulnerable children and young people?

11. Involvement of family members
Patrick's mother and maternal grandmother to be informed by letter by the BBSCB following discussion with the SCR Authors. Interviews with the family are to be scheduled with the SCR Authors.

12. Other parallel reviews/proceedings/investigations
None identified.

13. Media coverage
Jenny Myers, BBSCB Independent Chair will respond to media enquiries.

14. Legal advisor
Legal advisor to be identified via Bedford Borough Council as appropriate.

15. Liaison with Ofsted
Sally Stocker, BBSCB Business Manager.

16. SCR timescales
Review will be completed within the 6 month timescale.