Salford
Safeguarding
Children Board

Child R

Serious Case Review

Final Report

Contents

EXECUTIVE SUMMARY

Initiation of Serious Case Review

This review was initiated by Salford Safeguarding Children Board as a result of concerns Child R had been seriously harmed through neglect of his nutritional and medical needs. Both Adult A and Adult B were arrested but have since been released with no charge.

The children

There are three children within the family; practitioners and the parents confirm good relationships with each other and their parents. Child A and Child B were aged eight and six when Child R presented in a moribund condition, both were in primary education.

In school Child A presented as a confident outgoing child who was protective of her quieter, shy sibling, Child B. There were intermittent concerns regarding the two children's attendance at school, which at times dipped below the acceptable level. Highlighting this to the parents brought about improvements.

Child R had Short Bowel Syndrome. The condition affects absorption of water, vitamins, minerals, protein, fat, calories, and other nutrients from food which can put patients at risk of malnutrition, diarrhoea and dehydration. As a result, Child R required on-going additional nutritional support in the form of tube feeds into his abdomen and a central feeding line into a large vein. Child R also had some developmental delay associated with prematurity.

Child R was described by practitioners as a lovely boy, quietly spoken, always appearing happy.

The parents describe Child A as a 'wanna-be' celebrity who can be loud and outspoken in contrast to Child B who they describe as laid back, shy with new people, but very bright and intelligent. The two are said to alternately fight like cat and dog then cling to each other. Child R is the joker of the family who is polite, well mannered, generally quiet and calm but can be boisterous.

Summary of Case

The period covered by this review is the 45 months from the premature birth of Child R, in January 2012 to the date the parents were arrested for neglect in October 2015.

During this period, life for the family, and in particular Adult B, changed significantly. Child R's diagnosis of prematurity and intraventricular haemorrhages required careful monitoring of development and this, coupled with Short Bowel Syndrome, led to extended periods in hospital; initially NICU, then PICU and then on children's wards at local and tertiary hospitals. Child R needed a series of surgical procedures, on-going treatments and nutritional support.

Child R's complex health needs meant they required continued support from a large number of health practitioners, both in the community and from five hospitals. During this time Adult B took on responsibility for all Child R's additional needs, remaining with, or visiting daily, whilst Child R was hospitalised. Adult B performed many of Child R's cares whilst, at the same time, continuing to be seen as the head of the household by the professionals involved with the family

Adult A, a constant in the family, took on a more active role with Child A and Child B taking them to and from school and facilitating their contact with Child R and Adult B throughout Child R's hospitalisation. Adult A declined to be involved in Child R's additional medical cares. The reason for this was not known to the professionals involved with the family. Adult A indicated to the lead reviewer this was due to fear.

The family were supported by Adult A's mother who would care for Child A and Child B whilst the couple were at hospital with Child R.

Relevance to wider context of safeguarding children with disabilities

This review has unearthed an interesting difference in practitioner's perceptions around what constitutes disability versus a child with complex health needs, and therefore which services may be required.

The Disability Discrimination Act 2005 (DDA) defines a disabled person as someone who has "a physical or mental impairment which has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities." According to the DDA 'substantial' means 'more than minor or trivial' and 'long-term' means that it 'has lasted or is likely to last more than a year'. Applying this definition to Child R it is clear that he has a disability.

Research concludes,[1]Different agencies may use a variety of definitions of disability and the terminology used is the subject of much debate between professionals as outlined in the DCSF research report Disabled Children: Numbers, Characteristics and Local Service Provision (2008). These differences in the use of terminology may result in a loss of focus on the welfare of the child. The research found the key issue was not what definition of disability had been used but the impact of abuse or neglect on a child's health and development, and consideration of how best to safeguard and promote the child's welfare. In Salford, Children with Disabilities would be assessed by the Children with Disabilities team and appropriate services offered in line with current guidance[2].

[1] Murray, M. & Osborne, C. (2009) Safeguarding Disabled Children: Practice Guidance. DCSF: Nottingham
[2] *0 to 25 SEND code of practice: a guide for health professionals Advice for clinical commissioning groups, health professionals and local authorities* (February 2016)

Safeguarding concerns for disabled children can arise in a number of ways. One way, as in this case, arises from parents being seemingly unwilling or unable to follow medical and allied health professional advice and with consequent potential impacts on the child's health and/or development. On occasion Adult B would either challenge the decisions of the professionals or disregard their advice but not to a point where practitioners felt concerned that Child R's welfare was not being safeguarding until October 2015. Practitioners at the local tertiary hospital were aware that the family were reportedly suing the Trust and according to both parents and practitioners this appeared to have a negative impact on relationships.

Summary of Findings

The incident that led to the requirement for this review, could not have been predicted by the professionals working with the family. In the period prior to the incident no concerns of a safeguarding nature had been raised by any of the professionals working with the family.

There is no certainty that any of the findings below would have made any difference or prevented the incident from occurring.

The lack of recognition of Child R as a child with a disability meant there was never an assessment as such. An opportunity to provide early help services was lost when no action, other than to place Child R's name on the disability register was taken, following S85 notification of Child R's prolonged hospitalisation.

In order to provide the right support to any family with a child with disability or complex health needs it is important to understand the parent's needs. Practitioners had insufficient understanding of how the parent's backgrounds and experiences impacted on their views about disability, health and, in particular, social services. In part, due to Adult A and Adult B's backgrounds, they were unlikely to invite involvement of certain professionals into their family and even less likely to identify when they were struggling to juggle all their responsibilities.

Aspects of Adult B's manner, coupled with legal action the couple were taking against a health Trust, at times impeded the professionals working with the family. Adult B indicated to the lead reviewer an awareness that when feeling anxious they spoke quickly, and in a tone, others may perceive as threatening. The challenge for professionals is to find ways to work effectively in these circumstances and with those that do not readily agree or accept the advice given.

Throughout the period under review there were a number of occasions when professionals considered the use of CAF would be beneficial for the family, both to assess the whole family's needs and provide the appropriate early help services and support. Parents belief that the CAF was a social worker led process allied to Child Protection led to them declining the offers.

The lack of multi-agency approach and in particular the lack of an allocated Lead Professional led to a lack of co-ordination of services and appointments, and impeded information sharing within and between services. Professionals energies were spent on following up on missed appointments and on no access visits, rearranging them, rather than on direct outcome focussed interventions. This also impeded consideration of whether these factors were evidence of non-compliance or neglect.

Seemingly low level concerns are difficult to assess as a single agency and in isolation, making the use of supervision and multi-agency approaches essential.

Recommendations

1. All health professionals when taking initial histories should, in addition to obtaining the child's medical history, explore a family's previous experiences of health, as well as the family composition, the support network available for the family and parent/s and other needs of the family in relation to housing, monetary needs, health needs etc. when needed.
2. The SSCB in conjunction with the Regional network and its partners needs to ensure all its procedures and training includes complex health issues when relating to disability.
3. All Section 85 notifications of prolonged admissions to hospital of a child with a disability or with a complex chronic health condition should lead to an assessment of need by the Local Authority.
4. The SSCB health partners need to ensure multiagency participation is an explicit requirement at discharge planning meetings where a child has complex health needs or a disability. This involvement must commence early on so a Lead Professional is allocated to the child and family at the earliest point.
5. The SSCB partners need to develop pathways for counselling and support provision and ensure the level of service meets the population need and the needs of parents and carers of children with complex health needs and/or disabilities across Salford.
6. SSCB to ensure that policies set an expectation that professionals working with complex child health cases and those where there are barriers to open dialogue and challenge discuss this in safeguarding supervision and ensure concerns are shared with lead professionals, and that CAF guidance provides consistent advice that links to the 'threshold of need' and 'Uncooperative families' Greater Manchester policy.
7. A system needs to develop whereby Health Visitors working with children with complex needs/disabilities, who have school age siblings, are required to inform the appropriate school nurse.
8. Children Services to consider how CAFASS assessments can be shared across relevant partner agencies and with parents.

9. It should become routine practice that the children's social care representative in attendance at the strategy meeting informs the Lead Professional regarding serious incidents in order they can inform all the professionals involved. See Recommendation 12&13.
10. Local Authority to review the current practice regarding children living in hospital provision (Section 85 notifications) and provide an assurance report to the SSCB regarding how robust the process is.
11. SSCB health partners to agree a process to ensure all children with ongoing complex health and developmental needs are referred to Community Paediatricians before discharge from secondary/tertiary hospitals.
12. Salford SCB to agree with member agencies a consistent process for identifying the Lead Professional and the responsibility for the various functions of the Lead Professional.
13. The SSCB with the support of the Police, to develop multi-agency guidance for staff on their engagement with parents during criminal investigations e.g. the. do's and don'ts of discussions regarding their situation.

What will the LSCB do in response to this?

The LSCB and partner agencies have prepared SMART action plans which describe the actions that are planned to strengthen practice in response to the findings and recommendations of this serious case review.

1 INTRODUCTION

1.1 Initiation of Serious Case Review

1.1.1 This review was initiated by Salford Local Safeguarding Children Board following concerns that Child R had been seriously harmed; there was prima-facie evidence of medical and nutritional neglect. Two older children within the family were taken into Local Authority Care following the arrest of their parents.

1.1.2 Child R had short gut syndrome following complications of a premature birth, (necrotising enterocolitis) and bowel surgery. As a result, Child R had problems related to poor absorption of water, vitamins, minerals, protein, fat, calories, and other nutrients from food.

1.1.3 Child R was receiving additional nutritional support through a combination of Parenteral Nutrition (PN) and gastrostomy feeds which were being administered by Adult B within the family home.

1.2 Agencies and local authorities involved

1.2.1 Due to the complex needs of Child R there were different health agencies involved in his care. These agencies spanned across the boundaries of Manchester and Salford.

1.2.2 The following is a list of the agencies involved with the family and the services they offered. Where abbreviations have been identified these will be used throughout the report to denote the organisation the author is referring to:

- Salford Royal NHS Foundation Trust (for provider services)
  - Speech and Language Therapy Team
  - Occupational Therapy and Physiotherapy
  - Health Visiting
  - Diana Nursing Team
  - Community Paediatrician
  - School Nursing
- GP Services, NHS Salford, Clinical Commissioning Group
- Central Manchester Foundation Trust (CMFT)
  - Neonatal Team
  - Speech and Language
  - Consultant Gastroenterologist
  - Gastroenterology Specialist Nurse
  - ENT Sleep Studies
- North West Ambulance Service
- Greater Manchester Police
- Education
  - Starting Life Well Service
  - Higher Broughton Nursery
  - Oakland's Nursery

- Marlborough Road Primary School

- Salford City Council (Children's Services)
  - Emergency Duty Team
  - Duty and Assessment
  - Education Welfare Service
  - Looked After Children
- Housing
  - Salix Homes
  - Housing Options

In addition, a summary of involvement was requested from:

1. Abbott Nutrition
2. Calea UK Ltd Company which provided the PN machine

1.2.3 This has been a systems review, focusing on the strengths and weaknesses of the multi-agency system in supporting families and safeguarding children with complex health needs.

1.2.4 The review was managed by a review panel (see appendix 2), consisting of senior managers of the involved agencies, working with the independent Lead Reviewer. In recognition of the complex health issues for child R, the Salford Safeguarding Children Board chair, Simon Westwood, appointed an experienced Lead Reviewer from a health background (Nicki Walker-Hall).

1.2.5 The membership of the panel was agreed at the beginning of the process to include representation of the main agencies involved, and/or of those that commission their services.

1.2.6 The Case Review and Audit Sub-group and the screening panel decided the key focus points for the review and highlighted the following lines of enquiry for consideration:

- How can we understand the needs of children with disabilities as a multi-agency group better?
- How can we create stronger multi-agency systems to identify and intervene in situations of neglect, particularly if we are working across borough boundaries?
- Parental engagement appears to be minimal. Were the parent's needs overlooked? What counselling and support is available for parents with a disabled child?
- How can practitioners work together in a manner that takes account of a family's needs, yet keeps children's needs as the focus of intervention?
- What are the challenges to identifying matters of neglect when working with complex health situations across many health providers?
- Should only one parent be trained to administer PN feeds?
- Given the complexity of the case, was consideration given to appointing a lead professional at a sufficiently early point? Was consideration given as to which practitioner was the most appropriate lead professional? Was there confusion about the existence of, or identity of, the lead professional and the functions of the role?

- Was consideration given to holding a team around the family meeting to formulate plans and implement them?
- Is there evidence of escalation of concerns by any of the practitioners who felt at points that child protection processes should have been initiated? Was there over reliance on a medical consensus in initiating child protection procedures?

1.2.7 The process used included:

- Chronologies from all involved agencies
- Single Agency Analysis Reports (SAARs) from all involved agencies
- Panel challenge of the SAARs
- Resubmission of revised SAARs
- Individual and various group practitioner and management sessions to maximise learning for those involved with the family at the time, both in the SAAR stage and in the 'overview' phase of the review. Staff participation was good, showing commitment to learning; this participation increased understanding of the situation at the time, the reasons for actions (or non-actions) and decisions. Feedback from the learning events has been incorporated into this report throughout.
- The Lead Reviewer was given access to documents that formed part of the criminal investigation and legal process.

Timeline

- Screening Panel 23rd November 2015
- 1st Serious Case Review Panel- **26th February 2016**
    - Submission of 1st iteration SAARs – **31st March 2016**
- 2nd Serious Case Review Panel – **15th April 2016**
- SCR Briefing session – **29th April 2016**
- Learning Event – **17th May 2016**
- 3rd Serious Case Review Panel – **20th May 2016**
    - 2nd Learning Event – **24th June 2016**
- 4th Serious Case Review Panel- **27th June 2016**
    - Submission of 2nd iteration SAARs – **7 July 2016**
    - Submission of 1st draft Overview Report – **25th July 2016**
- 5th Serious Case Review Panel – **3rd August 2016**
    - Submission of 2nd draft overview report – **9th September 2016**
- 6th Serious Case Review Panel – **23rd September 2016**
    - Submission of 3rd draft overview report – **4th November 2016**
- 7th Serious Case Review Panel – **11th November**
    - Submission of final overview report – **5th December 2016**
- 8th Serious Case Review Panel and Case Review and Audit Subgroup Presentation – **9th December 2016**
- SSCB Presentation – **19th December 2016**
- Send SCR to Ofsted, DfE and the national panel **– March 2017**
- Publish SCR and Board Action Plan– **March 2017**
- Annual SSCB Learning from Case Reviews Event –**March 2017**

The timeframe from the outset did promote compliance with statutory timescales.

1.2.8 The timeline has been impacted by some of the parallel processes – please see section below.

Parallel Processes

1.2.9 The pace of this review was impacted by two parallel processes, the first being the criminal proceedings against the parents and the second the care proceedings in respect of all three children within the family.

Family participation

1.2.10 Adult A and Adult B wished to be fully involved with the review once the criminal processes had been completed. The lead reviewer, on the third appointment, met with both parents separately and together on one occasion, time was limited but the parents were able to provide their own views and experiences which has enriched the review . An invitation was extended to Adult A's mother, unfortunately illness prevented her involvement.

Limitations

1.2.11 The lead reviewer would have welcomed an opportunity to speak to Adult A's mother, believing this would have provided insight and a different perspective on the impact of Child R's illness on the whole family and the functioning of the family unit.

1.3 Structure of the report

1.3.1 The report is structured as follows:

- **Chapter 2** provides a summary of the overall context:
  - a summary of what happened
  - details of family members and a description of what was known about the children in the family, in particular Child R
  - An explanation of Short Bowel Syndrome
- **Chapter 3** describes what happened from the perspective of those involved at the time, including both professionals and family, explains the rationale for actions and decisions and appraises the practice
- **Chapter 4** provides an analysis of the themes emerging from the practice in this case:
  - chapter 4 considers the facts of the Chid R's health needs
  - chapter 5 explains the impact of complex health needs/disability on this family
  - chapter 6 discusses the professional and organisational practice
- **Chapter 5** provides the conclusions, overall findings and recommendations

2 CONTEXT

2.1 Summary of what happened

Parental background

2.1.1 This family had previous involvement with, and knowledge of, Local Authority Social Care. Both parents previously resided in a neighbouring authority and had themselves been cared for within the Looked After Children system for many years; drug and alcohol addiction were features of their parent's lives. They explained, to the lead reviewer, that they had a number of placements both with foster carers and in care homes and met whilst residing in the same care home. Some placements were happy, some were not and broke down and some ended due to closure of the care home. The couple felt they had a mixed experience of Social Workers, some were good others were poor and didn't relate. Adult B became pregnant with their first child (Child A) aged 15. The couple felt the support offered following the conception of Child A was poor, both financially and in terms of a placement offered which they felt unsuitable. Adult A was initially resistant to claim benefits wanting to earn a wage however eventually both Adult A and Adult B found themselves reliant on benefits.

Background prior to period under review

2.1.2 The parents had two older children prior to the period under review. Child A was born in 2006 and Child B in 2008. Child A was subject to a short period (3 months) on a Child Protection plan under the category of neglect in the same neighbouring authority, until a support plan could be put in place. At that time an assessment indicated there had been concerns that the couples' chaotic lifestyle, including drugs and alcohol, was impacting on Child A; additionally, it was reported the couple had no good role models themselves. The couple report whilst drugs and alcohol were an issue in the environment they had been placed, the couples use of drugs and alcohol was reported to be untrue, it has seemingly remained on their records and is referred to whenever there is a new contact, causing them upset. Child A was removed from the child protection plan after the couple had shown a high level of care and commitment to Child A. Adult B recalls attending a number of parenting courses which she enjoyed. The week following Child B's birth all Children's Services involvement in respect of Adult B ceased as she was transferred to Barnardo's after care services early.

2.1.3 Following Child B's birth there were no identified professional concerns about either child's care. The only notable involvement with acute illness and secondary health services was when Child B was treated for meningococcal sepsis aged 13 months.

2.1.4 The family had settled in the Salford area by the time Child R was born. The couple moved their family into a privately rented home in Salford; the couple wanted a better life for their children and saw this as a path to achieving this. Practitioners attending the learning events perceived the family were all living together with the exception of housing who thought Adult B was a single parent as her name was the only name on the housing application; the couple indicated their relationship has been a constant.

2.1.5 There was no indication to professionals that the family had any additional support other than Adult A's mother in caring for their children. The couple confirm a very limited support network, Adult B referring to Adult A's mother as her 'best friend'.

Period under review

2.1.6 The period covered by this serious case review begins from the date of the premature birth of Child R, in January 2012 to the date the parents were arrested for neglect in October 2015.

2.1.7 During this period the life of the family, and particularly Adult B, changed significantly not only with adjustment from being a family of four, to a family of five, but in taking on a significant care role for Child R following diagnosis of Short Bowel Syndrome. This diagnosis meant Child R's health care needs were complex and required extensive multi-disciplinary health input from primary, secondary and tertiary services across five hospitals and three geographical areas.

2.1.8 Child R spent the majority of his first year in hospital, Adult B spent significant amounts of time at hospital caring for Child R. It is common for there to be a significant period of emotional and practical adjustment for parents in these circumstances and additionally this affects all members of the family.

2.1.9 Thereafter Child R was admitted on multiple occasions with complications relating to the diagnosis of short gut syndrome and central line infections. Child R's complex health needs meant at other times, the family had numerous contacts with health practitioners, both in the community and from the hospitals involved, who offered care, monitoring, advice and support.

2.1.10 Adult B was perceived by professionals at the learning events to have responsibility both for the domestic sphere, and also for Child R's additional care needs. This involved monitoring Child R's health and wellbeing and performing many activities normally undertaken by qualified nurses in the hospital setting, for example, administering intravenous (IV) antibiotics and parenteral nutrition as well as gastrostomy feeding. Although Adult A was believed by health professionals to be an integral part of the family Adult A declined, for reasons unknown to the professionals involved, to actively participate in Child R's additional care needs; it was also noted Adult A didn't intervene when Child A and Child B were distracting Adult B whilst undertaking Child R's cares in the home.

2.1.11 In March 2012 Child A and Child B witnessed a domestic violence incident between Adult B's sister and her partner. This was reported to Salford Children's Social Care but there is no indication an assessment was done.

2.1.12 In May 2012 there were concerns when Adult B removed Child B from one hospital and transported the child to another hospital, where Child R was being cared for, against medical advice. This incident led to a Child Protection referral and completion of an initial assessment. The social worker recommended the Team around the Child process and services were offered to the family (tenancy support worker and family support worker) but these were declined. The assessment concluded that the level of concern did not meet the threshold for further intervention; Adult B indicated they were keen to take support from the school family support worker and the social worker agreed to facilitate contact

2.1.13 In October 2015 Child R was admitted in a moribund condition and diagnosed with dehydration, severe acidosis and hyperosmolar non-ketotic coma due to high blood sugars, raised blood sodium levels, acute kidney problems, developing subsequent fungal infection. A scan of the head identified sub-dural haemorrhages on both sides of Child R's brain.

2.1.14 As results of tests were received and Child R's blood glucose and sodium levels returned to normal quickly, safeguarding concerns were raised. This was coupled with Adult B commenting on home conditions and an inability to safely administer Parenteral Nutrition, Adult B's anxious and seemingly aggressive behaviours, and the loss of a pump that administered Child R's parenteral nutrition. Hospital staff referred the case to Children's Social Care and the Police for investigation four days after admission.

2.1.15 The Police commenced their investigations and the following day both parents were arrested.

2.2 The Family

2.2.1 The parents are White British having lived in or around the Salford/Manchester area for all their lives.

2.2.2 Table 1 shows the family composition living in the household in Salford. Additional support was provided by Adult A's mother. Adult B's father features within this review only in so far as Adult B put herself forward as a potential carer for his child, her half-sister when there were Child Protection concerns.

TABLE 1

Term used in report	Relationships	Age in October 2015
Child A	Eldest child	8 years
Child B	2nd eldest child	6 years
Child R	Subject of the review	3 years 9 months

Adult A	Father of all the children	27 years
Adult B	Mother of all the children	25 years

The children

2.2.3 There are three children in the family and those practitioners who had opportunity, observed that they had good relationships with each other and with their parents. The eldest children were 5 and 3 when Child R was born.

2.2.4 The two older children had no additional health or educational needs; both were in mainstream primary education, attending the same school. Child R had developmental issues relating to prematurity and Short Bowel Syndrome as a result of bowel resection affecting his gut absorption (see section 2.3).

2.2.5 Practitioners described Child A as a pre-pubescent, confident child who liked dressing up, but often wearing inappropriate shoes. Parents indicated she can be loud and at times outspoken with a desire to become a singer. Child A was said to be very protective of Child B who was described as quite sombre, much the quieter of the two, seemingly shy, and in the professionals' opinion, insecure and needy of adult attention. Parents describe her as more 'laid back', bright and intelligent. The pair are said by parents to alternately fight like 'cat and dog' or 'cling' to each other.

2.2.6 Child R had recently commenced at nursery school and was described as a lovely boy, quietly spoken, always appearing happy. He engaged well with practitioners involved in his care, and liked to be able to see Adult B. Other children took to him well and he made good progress at nursery. Health staff stated that he engaged with therapy and was often giggling and happy. Parents describe him as 'the joker of the pack', polite and well mannered.

Family Dynamics

2.2.7 The couple appeared to professionals to have very separate roles with the children with Adult B seemingly at the helm. Adult A had a clear role in transporting the older children to and from school. Any additional input into schooling was however Adult B's domain. This appeared less marked for the couple themselves.

2.2.8 Hospital staff were under the impression that Adult B provided the majority of care for both Child R and their siblings, although Adult A was present at some hospital admissions and facilitated visits from Child A and Child B. Adult B was described as good with and encouraging of Child R. Adult A indicated they took on normal parenting duties with all the children but left medical care to Adult B.

2.2.9 Professionals involved with the family were aware that Adult A's mother was involved with the family and on occasion Adult A was reported to have gone to live with her. Housing also believed Adult A's mother was supportive, Adult B having requested to be housed near to her for that reason. The couple indicated their relationship was solid and constant.

2.2.10 There was some contact with Adult B's father who, it is stated, used drugs and alcohol and whose child Adult B had considered caring for during a particularly concerning period.

2.3 Short Bowel Syndrome

Nature of the condition

2.3.1 Short Bowel Syndrome, or SBS, is a rare, life-threatening gastrointestinal disorder in which patients are unable to maintain nutrient and fluid balances with a normal diet.[3][4][5]

2.3.2 SBS generally occurs when a large portion of the small intestine has been removed by surgery for a variety of reasons, resulting in the loss of intestinal absorptive capacity but can also occur when the intestine loses the ability to function properly as a result of other disorders.

2.3.3 This means that patients can no longer absorb enough fluids and nutrients from liquids and food they digest to maintain good health. This is known as malabsorption, and can put patients at risk of malnutrition, diarrhoea and dehydration.

2.3.4 SBS can have a negative impact on a patient's quality of life because it restricts or alters their lifestyles. However, with the right treatment and disease management, these restrictions can be attenuated.[6]

Potential Problems

2.3.5 The complications of short gut syndrome may include:

- Malnutrition
- peptic ulcers—sores on the lining of the stomach or duodenum caused by too much gastric acid
- kidney stones—solid pieces of material that form in the kidneys
- small intestinal bacterial overgrowth—a condition in which abnormally large numbers of bacteria grow in the small intestine

Care

2.3.6 Treatment for short gut syndrome is based on the patient's nutritional needs. Treatment may include:

- nutritional support
- medications
- surgery

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[3] Hofstetter S, Stern L, Willet J. Key issues in addressing the clinical and humanistic burden of short bowel syndrome in the US. *Curr Med Res Opin* 2013;29(5):495–504.

[4] Jeppesen PB. Spectrum of short bowel syndrome in adults: intestinal insufficiency to intestinal failure. *JPEN J Parenter Enteral Nutr* 2014;38(1 Suppl):8S–13S.

[5] O'Keefe SJ, Buchman AL, Fishbein TM, et al. Short bowel syndrome and intestinal failure: consensus definitions and overview. *Clin Gastroenterol Hepatol* 2006;4(1):6–10.

[6] Kelly DG, Tappenden KA, Winkler MF. Short bowel syndrome: highlights of patient management, quality of life, and survival. *JPEN J Parenter Enteral Nutr* 2014;38(4):427–37.

- intestinal transplant

2.3.7 The main treatment for short gut syndrome is nutritional support, which may include the following:

- **Oral rehydration.** Children should drink oral rehydration solutions—special drinks that contain salts and minerals to prevent dehydration—such as Pedialyte, Naturalyte, Infalyte, and CeraLyte, which are available on prescription.
- **Parenteral nutrition.** This treatment delivers fluids, electrolytes, and liquid vitamins and minerals into the bloodstream through an intravenous (IV) tube—a tube placed into a central vein. Health care providers give parenteral nutrition to people who cannot or should not get their nutrition or enough fluids through eating.
- **Enteral nutrition.** This treatment delivers liquid food to the stomach or small intestine through a feeding tube a small, soft, plastic tube placed through the nose or mouth into the stomach, or a tube/button placed on the tummy which enters directly into the stomach. Gallstones—small, pebble like substances that develop in the gallbladder—are a complication of enteral nutrition.
- **Vitamin and mineral supplements.** A person may need to take vitamin and mineral supplements during or after parenteral or enteral nutrition.
- **Special diet.** A health care provider can recommend a specific diet plan for the patient that may include
    - small, frequent feeds
    - avoiding foods that can cause diarrhoea, such as foods high in sugar, protein, and fibre
    - avoiding high-fat foods

2.3.8 A health care provider may prescribe medications to treat short gut syndrome, including:

- antibiotics to prevent bacterial overgrowth
- H2 blockers/proton pump inhibitors to treat too much gastric acid secretion
- choleric agents to improve bile flow and prevent liver disease
- bile-salt binders to decrease diarrhoea
- anti-secretin agents to reduce gastric acid in the intestine
- hypomotility agents to increase the time it takes food to travel through the intestines, leading to increased nutrient absorption
- growth hormones to improve growth if there is associated growth hormone deficiency
- teduglutide to improve intestinal absorption

2.3.9 The goal of surgery is to increase the small intestine's ability to absorb nutrients. Approximately half of the patients with short gut syndrome need surgery.[2] Surgery used to treat short gut syndrome includes procedures that

- prevent blockage and preserve the length of the small intestine
- narrow any dilated segment of the small intestine
- slow the time it takes for food to travel through the small intestine
- lengthen the small intestine

2.3.10 Long-term treatment and recovery, which for some may take years, depends in part on

- what sections of the small intestine were removed
- how much of the intestine is damaged
- how well the muscles of the intestine work
- how well the remaining small intestine adapts over time

The role for parents

2.3.11 Parents often take on an extended role when caring for children with complex health needs/disabilities. Much of the extended role encroaches into what is commonly understood to be a nursing role with parents undertaking tasks usually assigned to qualified nurses in the hospital. Parents are trained and supported to undertake this role.

2.3.12 The basics of feeding can be quite onerous, with parents being encouraged to learn how to administer feeds either directly into the stomach via a tube, or intravenously or both (as in Child R's case). Some of the pleasure and intimacy usually associated with infant feeding is lost and feeds can become more of a task. Feeding can be either continuous or more frequent than usual, and can be time consuming, as feeds may require increased preparation and tubes require care pre and post feeding.

2.3.13 The change in role from parent to parent/carer has the added dimension of putting the parent in control of much of their child's nursing care. Parents of children with complex ongoing health needs are often viewed as the expert in their child's needs and care in a way that would not be expected of parents whose child had a general or acute illness.

2.3.14 Parents of children with complex health needs/disability often report increased tiredness, in part due to their caring responsibilities with increased numbers of routine check-ups and appointments for review and for treatment, but also as a result of the emotional toll associated with their caring role.

2.3.15 The increased care needs can result in a reduction of opportunities for parents to socialise and to stay involved with friends and remain active in their communities. This can result in isolation and loneliness.

2.3.16 It is not uncommon for parents to go through the grieving process, particularly if their child is not developing and progressing as they had anticipated.

2.3.17 Caring for children with complex health needs/disability can cause strain within the most stable of relationships, and if there are existing relationship difficulties or inequalities these often become amplified.

3 NARRATIVE AND APPRAISAL OF PRACTICE

3.1 Introduction

3.1.1 The period under review covers the date from the premature birth of Child R, in January 2012 to the date the parents were arrested in October 2015.

3.1.2 In order to gain an understanding of the circumstances that led up to this point, the time period under review has been divided into a series of manageable episodes. Crucially, not all the activity that was focussed on Child R and his family on an ongoing basis is explicitly listed so it is important to keep in mind the significant amount of professional activity/energy that was being concentrated on the family

3.1.3 This chapter explains what happened, with a 'comment' box providing an appraisal of practice for each key practice episode.

3.2 Key Events

1 January 2012 – September 2012 Birth of Child R to discharge

3.2.1 Child R was born in January 2012 at 29 weeks' gestation weighing 1665gms and requiring resuscitation. Initially Child R was admitted to the neonatal unit at Hospital 1 with prematurity, suspected sepsis and respiratory disease of the newborn and found to have a Grade 2 Intraventricular Haemorrhages (bleeds on the brain).

3.2.2 Whilst Child R's care was administered during this period within secondary and tertiary care, primary care services were made aware of his birth; the allocated Health Visitor conducting a primary visit to introduce herself to the parents at the hospital.

3.2.3 Other services and professionals involved with the family, in particular Child A and Child B's school, were less aware of the circumstances surrounding Child R's premature birth and subsequent health issues. Child R's birth coincided with a temporary increase in absenteeism of Child A and Child B.

3.2.4 Within two weeks of birth, Child R developed necrotising enterocolitis (NEC) which is the most common surgical emergency in newborn babies and tends to affect more babies born prematurely than those born full-term. NEC is a serious, life threatening illness in which tissues in the intestine (gut) become inflamed and start to die. This can lead to a perforation (hole), which allows the contents of the intestine to leak into the abdomen. Child R initially underwent emergency bowel surgery and had a resection of his small intestine causing the short gut and formation of duodenostomy.

3.2.5 Child R received specialist neonatal care until late March when he was discharged to a children's ward for on-going treatment of his short gut syndrome. Child R had further planned bowel surgery as part of the treatment of his condition in March and April.

3.2.6 Due to being unable to absorb nutrients in his small bowel, Child R required Parenteral Nutrition for feeding. Child R also required additional feeds and fluids via a tube into the stomach. Adult B underwent extensive training to administer both of these feeds and his prescribed regime. His regime changed periodically in response to regular weight monitoring and blood tests. Child R was also prescribed dioralyte for times when he was unable to tolerate solids and needed additional hydration.

3.2.7 During Child R's admission the couple were experiencing housing issues; their landlord indicated he was pursuing court action with a hearing scheduled in April 2012.

3.2.8 Adult B sought help from Housing Options. A homelessness application was triggered and forms were sent to Adult B for signing. No referral was made to Children's Services by Housing Options, as no concerns were identified and there were services in place in relation to Child R's needs. The neonatal unit were aware of the issue but also did not identify a need to refer to any other services.

3.2.9 The HV made a further visit to Child R and in recognition of his complex health needs weighted his care needs as level 3.

Comment:

In these early weeks there were signs that the family had a number of competing priorities. A sick child, hospitalised for a number of weeks is well recognised as a strain on families. Adult B became the main carer for Child R frequently staying overnight or visiting daily and beginning a programme of training in order to be able to care for Child R's nutrition, after his discharge. The plan of care was not marked as completed in its entirety, however Adult B was assessed as competent.

Hospital staff, aware of the couples housing issues, provided supporting letters to housing. However, they were unaware Adult B was applying for housing individually, believing the family members were all residing together as a single family unit.

The Health Visitor weighted Child R's needs at level 3 in recognition of the complexity of his health needs. This decision indicates an increased level of input would be required, Child A and Child B's childhoods undoubtedly changed following Child R's birth, however little is known about the impact on Child A and B and no information is noted to have been shared between health visiting and school nursing.

Except for housing, all the professionals involved in Child R's care were predominantly focussed on his complex health needs. Completion of a CAF at this point may have provided a more holistic view of the family and their individual needs See section 5.2

3.2.10 Child A and Child B witnessed a domestic violence incident involving Adult B's sister and partner whilst in their care; the couples' children were known to Children's Social Care however Child A and Child B were not considered as at risk, so no further action was taken.

Comment:
The circumstances around this incident are largely unknown. The incident did not involve the children's parents, what we don't know was how frequently Adult B's sister was caring for Child A and Child B. There was no communication regarding this incident with school nursing, education or the Children's Centre, so there was no opportunity to assess or address any emotional impact. This opportunity for an assessment had the potential to bring to light any difficulties the couple were facing in meeting all their children's needs. This has been addressed and recognised in the recent JTAI inspection. The Board initiated and supported a pilot project to share domestic abuse notifications with schools. This will be embedded into the Tackling Domestic Abuse Board (TDAB) and therefore no recommendation is made.

3.2.11 In mid-April, homelessness full duty was awarded. Adult B, Child A and Child B were to be placed in Bed and Breakfast accommodation; parents indicated the landlord allowed them to remain at the address until suitable accommodation was sourced.

3.2.12 School became aware of the housing issues when Child A and B were absent from the school. Adult B agreed to complete a CAF with school. In the meantime, Child B became unwell with shortness of breath and was admitted to Hospital 3 A&E. Adult B took Child B, against medical advice to Hospital 2 where Child B was admitted for the evening. Hospital 3, concerned, referred the incident to Children's Services and the case was opened by Children's Services for an initial assessment. School were advised by Children's Services; the CAF they were planning was not necessary in view of the initial assessment. The initial assessment concluded that the risk of a repeat of the situation was small. The general concerns regarding the parents' ability to cope with their current circumstances were noted, as was the parents' refusal for support from a Tenancy Support Worker and TAC. It was recorded that the level of concern did not meet the threshold for further intervention and thus the case was closed.

Comment:
The information used to inform the initial assessment came mainly from health sources and Adult B, and was focused on the incident. That a core assessment might be helpful was not considered. There appears to have been no discussion with Housing and it is not clear whom, within the school, the social worker spoke with or what information was shared. Adult A and Adult B informed the lead reviewer they understood CAF/TAC to be social work lead and part of child protection, and as such, not something they would willingly embrace because of their previous experiences. At the time Adult B expressed an interest in knowing more about the school Family Support Worker and whether they were able to support the family in getting the children to school. The social worker indicated this would be progressed when the Family Support Worker returned from leave, however there is nothing to indicate this was communicated with the school nor that it was followed through. Feedback to the school would have allowed the staff to offer support in an alternative way the couple may have found more acceptable and offered an opportunity to assess and deliver support to the family. A

step down process to TAC is now in place.

3.2.13 Housing Options continued their support of the family in respect of housing.

3.2.14 Hospital 2 sent summaries of Child R's treatment to all the health professionals, in line with the recommendations of the Initial Assessment, who were to have on-going involvement with Child R. The summaries identified that Child R would be discharged on Parenteral Nutrition (PN) and a bowel expansion programme.

3.2.15 In June 2012 a pre-discharge planning meeting was held. The GP, Housing and the Community Paediatrician were not present. Physiotherapy and Occupational Therapy indicated Child R had developmental delay and that he would benefit from on-going developmental advice in the community. The following week Child A and Child B were absent from school, Child A was said to have Chickenpox. Two weeks later Child R was transferred to PICU with a fever and deterioration in his condition; he remained there for an extensive period with a diagnosis of sepsis. Child R had a further brief admission to PICU with a suspected line infection. Absenteeism relating to housing and transport issues continued for Child A and B.

3.2.16 In August 2012 Child R had further planned bowel surgery; the hospital continued to prepare for Child R's discharge which took place in early September.

Comment:
The pre-discharge planning meeting was an opportunity to bring all professionals within primary, secondary and tertiary care together and was good practice. This meeting provided an opportunity to allocate a Lead Professional but this did not happen. It is unfortunate that there was a delay in discharge. This meant there was a considerable time between the original discharge planning meeting and discharge. During this time there had been many difficulties for the family with regards to housing and absenteeism relating to transport issues. Adult A indicated a 40-minute walk for the children to and from school was impacting. A multi-agency meeting at this point could well have influenced both the discharge date and the package of care and support offered.

3.2.17 Child R's weight was 5.1kg <0.4th centile, he was in receipt of PN and oral feeds of formula milk. Within 3 days of discharge Child R was re-admitted to Hospital. Adult B noticed he had a sunken fontanelle and felt Child R looked dehydrated and acted appropriately on her concerns

Comment:
Adult B demonstrated she was able to recognise Child R's change in condition and took appropriate action in returning him to Hospital. There is no discharge letter in the GP records pertaining to this admission. An audit has not demonstrated this as a systemic issue.

3.2.18 Two days later Adult B's tenancy commenced.

October 2012 – December 2012: Child R has two central line infections

3.2.19 During this period Child R continued to receive care from primary, secondary and tertiary services and underwent further planned bowel surgery, he also had a developmental assessment by the physiotherapist and occupational therapist. There were two admissions with line sepsis in this period. The first resulted in a 5-day stay before discharge with Intravenous Antibiotics to be administered by Adult B after discharge. The second admission was due to bronchiolitis.

3.2.20 Admissions led to a missed appointment with the Health Visitor.

3.2.21 The family's change of address impacted a referral to the speech and language therapy feeding team and a developmental assessment by the physiotherapist.

3.2.22 The Specialist Paediatric Nurse requested the Health Visitor monitor Child R's weight and refer Child R to the Community Paediatrician.

3.2.23 During this period housing issues continue as satisfactory payments were not being made. Adult B is notified that a Notice of Seeking Possession would be served the following week if no arrangements to pay were made.

3.2.24 Adult B was proactive in informing SPN PN of seeking GP assistance as Child R had a cough and cold. Child R had an OT/PT initial assessment and a further appointment was made.

Comment:
It appears that at this point there is a lack of co-ordination of roles, appointments and assessments. Professionals are working in silos and lack of information sharing was causing unnecessary work load. The sharing of basic demographic details may have prevented missed appointments and wasted home visits. There remain additional stressors for the family that health professionals were unaware of. CAF, if better understood and agreed by the family, could have increased understanding of the family's circumstances and brought about a holistic approach promoting information sharing and a co-ordinated plan of support that would be reviewed and would have led to the allocation of a Lead Professional. Adult B reported to the lead reviewer that she was discouraged from seeking GP assistance and instructed by the SPN PN to direct all health concerns to secondary and tertiary hospitals. Adult B indicated she felt she was given considerable authority at this time to take bloods and administer antibiotics and that a multi-agency plan would have helped.

Jan 2013 – March 2013: This period includes two contacts to Children's Services.

3.2.25 During the next three months, there continued to be confusion and a pattern of missed appointments in the community with the physiotherapist. Sometimes when appointments were missed, it was because Child R was in hospital, however on one occasion, Adult B stated Child R had been in hospital, which was not true. The community nursery nurse referred Child R to the community paediatrician some two months following initial request. Child R continued to attend short gut clinic; there were no concerns regarding his progress. Wt 6.3kg

3.2.26 Issues with non-payment of rent continued with attempts by the income officer to speak to Adult B.

3.2.27 During this period Child A had 1-day absenteeism for a temperature and Child B had routine growth measurement in school

3.2.28 In February Child R was seen in the gastroenterology clinic, the following day he was admitted via A&E. Child R had become unwell with a raised temperature whilst having his PN via a central line. A central line infection (3) was suspected and IV antibiotics commenced. Child R was discharged 5 days later – wt 6.7kg

3.2.29 During this admission Child R failed to attend his 1st SALT appointment; he was discharged, as per policy at the time and the referrer advised.

Comment:
Adult B appeared to be prioritising appointments with the Hospital Consultant relating directly to Child R's Short Bowel Syndrome, whilst appointments with community health care professionals are more frequently missed. Without clear communication lines, the Hospital staff formed a view that Adult B was compliant however the picture is not the same for other services. CAF and TAC process with an identified Lead Professional could have promoted information sharing and a co-ordinated plan of support that was reviewed.

3.2.30 There were concerns that Child B possibly had 2 bruises/nappy type rash. The school rang CS for advice as they couldn't contact Adult B. The family had changed address without informing the school. There's no record of this contact at CS however school indicate they were advised to speak to the parents which they did. Adult A took Child B to school the following day, Child B was checked in Adult A's presence, and no bruising or rash were present.

Comment:
The actions or inactions around this concern have been difficult to analyse. School staff were right to contact Children's Services for advice; the lack of recording of this contact within Children's Services means the reviewer is unable to establish whether practice was in line with policy at that time. It is difficult to establish the advice given and the processes followed which may have been anywhere from entirely appropriate through to warranting a medical opinion. However, this lack of recording is concerning. Whilst

children's services have been assessed by various agencies and reported as having good systems in place for safeguarding it should be checked to ensure advice given to professionals is routinely recorded.

3.2.31 During this period a number of requests came from one medical professional to another, the GP was requested by the hospital, to prescribe long term treatment for decontamination of the gut and the Neonatologist requested the GP conduct a neurodevelopmental assessment. Over the following months there was infrequent ordering of these treatments by the family indicating possible non-compliance and no evidence the GP carried out a neurodevelopmental assessment or made a referral for a Paediatrician to complete this.

Comment:
Within GP surgeries there have long been systems for monitoring the over ordering of medications however there is no system to monitor under prescribing of medication essential for patients to maintain or achieve optimal health. The responsibility for this now lies with the allocated GP. This information could then feed into other assessments/review processes i.e. CAF. Adult A and Adult B indicated much of the medication was prescribed by the tertiary hospitals.

3.2.32 The GP is informed by Adult B that Child R has a further SALT appointment; they have been promised a co-ordinator but this has not happened.

3.2.33 Child R has a further admission for a temperature due to a line infection (4) and not having had his Bowels Opened.

3.2.34 The GP was requested to increase Child R's dose of Ursodeoxycholic acid; this did not happen.

Comment:
The lack of a Lead Professional to co-ordinate all the requests and information means there are a lot of requests for primary care from secondary and tertiary care services with little evidence of a positive effect.
Hospital 2 were clear within their SAAR that there is a firm arrangement that GPs act as the single point for all information to go to and will cascade that information. The GP needs to be clearly notified that he/she needs to cascade the information. There is a lack of clarity as to whether that was fully understood by the GP practice involved or the hospital.
Whilst the GP was notified of action such as prescription continuation or alteration, the GP was not notified of all the prescriptions issued by the hospital. There is a need for providers to notify GP's of actions to be undertaken such as prescription continuation or alteration, cascading information to relevant specialities and making onward referrals.
Child R has had four line infections at this stage. It is clear that parental competence was in the mind of the gastroenterology specialist nurse who was supporting Adult B and assessing, if not documenting, her technique however, there is a lack of clarity about what will trigger parental competence to be formally rechecked.

April 2013 – June 2013

3.2.35 During this period there were a number of different appointments with various professionals. The mixed picture of compliance continues with Child R being seen by the physiotherapist at home who encountered a no access visit on another occasion, when Adult A stated Adult B had gone to the GP and forgotten, despite a text reminder. On another occasion Child R was presented for a Physiotherapy review of gross motor skills – it was felt he no longer needed specialist seating.

3.2.36 Child R was not taken to a community paediatrician appointment; Adult B citing non receipt of appointment.

3.2.37 The children's community nursing team discharged Child R in consultation with SPN as no input was deemed to be required. At that time Child R was undergoing a trial of no PN 1 night per week; dioralyte was prescribed to support hydration. The HV was active with the family and carried out weight checks pre and post two separate nights off PN and was informed by Adult B she had been assessed as still competent in her care of Child R.

3.2.38 The GP responded immediately to a request from gastroenterology for increase in prescribed dose of Ursodeoxycholic acid.

3.2.39 During this period the HV made multiple no access visits whist Child R was in hospital. On the first occasion Child R attended A&E with a temperature and was later admitted with a further line infection (5) Bloods were suggestive of sepsis and blood results indicated low sodium; thus Child R was re-admitted for central line removal and for gastrostomy. On the second occasion Child R was attending an Ophthalmic review for a possible intermittent squint; Child R was for further review in September 2013. There was a further no access visit for the HV with no apparent reason given.

3.2.40 Housing issues continue with Adult B being informed of their intent to recover possession of the property if there was no contact within 7 days. Adult B made contact and was informed an income officer would be in touch. Adult B later rang housing to advise an arranged home visit would be difficult as Child R was in Hospital; arrangements were made to pay the arrears.

July 2013 – September 2013

3.2.41 The Health Visitor offered to refer Child R to portage, Adult B declined this on the basis that there was input from other services. Child R had four admissions during this period:

- The first was planned for a PEG[7] insertion in early July;
- The second with low sodium and weight loss; sodium chloride was prescribed.

[7] Percutaneous endoscopic gastrostomy (PEG) is an endoscopic medical procedure in which a PEG tube is passed into a patient's stomach through the abdominal wall

- Child R had a further admission with central line sepsis wt 8.1 kg.
- Child R was further admitted with vomiting for 3 days

3.2.42 On the day of Child R's PEG insertion Child A and B were absent from school with no reason given. Child A and Child B were also absent four days later.

3.2.43 Following PEG insertion, the Diana team become involved. Adult B was carrying out all Child R's cares having been taught in hospital, and so was advised to contact the CCN if any input was required.

3.2.44 The Physiotherapist visited Adult B who reported Child R had not received an appointment with the Paediatrician yet. During one admission Child R missed a physiotherapy appointment which was followed up by the physiotherapist; Hospital 2 informed of impending discharge.

3.2.45 During this period` the housing Income officer left a message for Adult B regards non-compliance with a rent arrears agreement. The message was ignored and a further letter sent.

3.2.46 Child R had a change to diet to help with bowel frequency and aid weight gain; gluten free products were prescribed. Child R's regime was changed to 5 nights' parenteral nutrition plus milk per week, his weight was 7.86kg off PN.

3.2.47 The SPN PN re referred Child R for SALT. There was no HV involvement during this period.

Comment:
During this period there is evidence that Adult B was struggling to manage all her responsibilities and as a result the two older children's schooling was impacted and the family's housing placed in jeopardy. The professionals involved deemed Adult B to be competent in the care of Child R, however there was little evidence, that the impact of her caring role was being assessed. The onus was placed on Adult B to request help rather than a more helpful coordinated response e.g. a reactive rather than proactive service. An offer of CAF and a multi-agency response at this point may have been helpful despite previous refusal.

October 2013 – December 2013

3.2.48 There were a number of activities relating to housing during this period. Housing issued a Notice of Seeking Possession for rent arrears; however, they continued to take care of the property, carrying out three visits where they conducted repairs to a door lock and leaking toilet, made safe a ceiling in the kitchen, repaired a bathroom light and boiler, and plastered the kitchen ceiling. Adult B called to speak to the income officer; the call was returned but contact was not successful.

3.2.49 Adult B sought advice from the SPN PN as Child R was not coping with alternate night feeds. Adult B felt Child R was dehydrated by the afternoon. The SPN PN agreed to attend and review Child R the following week.

3.2.50 Child R had two further admissions with line infections. On a further occasion Child R attended with a temperature and vomiting. Adult B initially refused admission however returned later.

3.2.51 Child A was absent from school for 1 day with vomiting

3.2.52 Child R had another brief 1-day admission with a raised temperature weight 9.3kg and attended a hospital appointment for weight check and hub change.

3.2.53 The Physiotherapist visited Adult B and agreed to re-refer Child R to the community Paediatrician with regard to gross motor delay. Adult B indicated she was happy with Child R's progress. Adult B was reportedly keen at this point for local services to be co-ordinated.

Comment:
Adult B indicated she felt there was a need for better co-ordination of care. This provided staff with an opportunity to further discuss and initiate a multi-agency response via CAF, TAC and allocate a Lead Professional.
There are a number of reasons why there can be a discrepancy between parents and professionals view on a child's progress. In part this may be due to parents' expectations, particularly with a sick or preterm child, but it can be difficult for any parent to remain objective around their own child's development. Professionals are not just looking for a child to progress, they are looking for a child to reach recognised milestones in their development.

January 2014 – March 2014

3.2.54 The tenancy officer made a home visit to discuss medical waste removal some fifteen months post initial discharge.

3.2.55 Child R attended a follow up appointment with the paediatric surgeon and dietician with plans to review in one month; medication was increased.

3.2.56 Child R had a failed appointment with the physiotherapist and had an emergency admission with vomiting and a two-week history of a virus; Adult B had not sought GP advice. Adult B wanted to take Child R home without completing treatment and voiced concern about the care provided, however the Consultant made it clear, Child R needed to stay and complete treatment for a line infection and the consequences of not doing so. Child A was absent through illness however Child B was absent as Adult B indicated there was no one to take Child B to school as Child R was in hospital. It is not clear why Adult A or Adult A's mother could not do this. School advised Adult B to ask school to transport if there was a problem the following day.

3.2.57 Adult B requested the HV weigh Child R. The named HV had left, and the case had yet to be reallocated. In response to Adult B's request for Child R to be weighed, the nursery nurse made a home visit, Adult B expressed concern as Child R had lost weight. The following day Child R was admitted with seizures and low blood sugar – Child A and B were late for school as a result.

3.2.58 The physiotherapist completed a home review; Child R was making good progress.

3.2.59 In February Child R was admitted to PICU for a stricture release and bowel lengthening procedure. The physiotherapist kept in contact throughout admission. The Community Paediatricians appointment could not be attended due to Child R's hospitalisation. SALT took a decision to discharge until Child R was discharged by Hospital and left it to the hospital to re-refer. Abbot attempted to contact Adult B to check if their equipment was still required and to discuss deliveries. There were no discharge letters sent or pre discharge meetings.

3.2.60 Adult B agreed for an application to be made for a deduction of benefits, this was successful and there were no further issues with arrears.

3.2.61 Child R was discharged from Ophthalmology due to two failed appointments.

3.2.62 In March the Paediatric surgeon and dietician reviewed Child R who was reported to be tired during the day following a night off PN. Adult B was advised to give Child R x 2 sachets of dioralyte. Child R's weight was 9.6kg. Bloods were taken and showed low potassium; as a result, Child R was admitted. Child A and B had a 1-day unauthorised absence.

Comment:
It is not fully understood how Adult B was managing at this point, she had expressed a desire for co-ordination which hadn't resulted in a change of strategy. The consultant acted appropriately when explaining likely consequences of Adult B removing Child R thus promoting the *need of the child whilst considering the best outcomes for Child R. Adult B's desire to take Child R home at a point staff felt would be detrimental to his health, could have been borne out of difficulties in managing all her responsibilities and in particular getting Child A and Child B to school.*
The decision of SALT to discharge Child R was in accordance with policy at that time, however this then placed responsibility for re-referral on other professionals and open to oversight. Policy has now changed and this would not be the practice now.

April 2014 – June 2014

3.2.63 The physiotherapist remained active conducting a home review; Child R was progressing and Adult B was reportedly pleased. On the same day Child R missed an appointment with the community Paediatrician; his neuro developmental assessment remained outstanding. Adult B was to be advised by the physiotherapist of a referral to the Starting Life Well service for an early support key worker.

3.2.64 Child A and B continued to have a number of school absences, once for 2 days with no reason/explanation given and on another occasion with a tummy bug.

3.2.65 Child R had a dietician review. Adult B was advised to recommence bolus gastrostomy feeds as Child R had lost weight – 9.36kg.

3.2.66 Child R had two further admissions for line infections, on the first his weight had increased to 10.2kg, during the second the Community Paediatricians appointment was missed again. The physiotherapist was advised to complete a CAF; no safeguarding concerns were noted.

3.2.67 3 months after Adult B's request for a Health Visitor to weigh Child R a HV was allocated. At this point Child R has had no 9-month developmental check or 2-year developmental check as per the Healthy Child Programme.

3.2.68 SPN PN conducted a home visit to review Adult B's care of Child R's line following numerous admissions with line infections. The visit was followed up with a letter to both parents detailing the advice given.

3.2.69 The physiotherapist visited the home and was informed Adult B was suing the surgical team. Adult B was tired and unwell, thought to be due to constant visits, CAF was discussed and the initial questions completed. The CAF was completed 5 days later with a plan to check it with the family. Child A and B were absent from school; it was reported their uniforms were ruined in the washer.

Comment:
As a result of repeat admissions and in part due to the lack of allocated Health Visitor Child R has missed his routine developmental assessments as well as his neuro developmental assessments. This is a concern as without these assessments it is difficult to judge whether he was receiving the appropriate level of support and care to ensure he reached his optimum potential. An appropriate single agency recommendation has been made to manage vacant caseloads and address this issue.

July 2014 – September 2014

3.2.70 The physiotherapist referred Child R to ENT for snoring, Child R is reviewed and referred for a sleep study.

3.2.71 Child R failed to attend a community paediatricians' appointment; on this occasion he was not in hospital.

3.2.72 Child A and B have two short periods of absence during this period, the first without any reason given and the second with head lice.

3.2.73 Child R was seen by the gastroenterologist and dietician wt 11.05kg. PN was reduced to 4 x a week with 6 concentrated feeds. Child R was to have a trial of inhaler for his breathing

3.2.74 Child R was seen by the gastroenterologist and dietician wt 11.05kg. PN was reduced to 4 x a week with 6 concentrated feeds. Child R was to have a trial of inhaler for his breathing.

3.2.75 The Dianna CCN noted Child R had a dirty PEG end and made arrangements for it to be changed. The following visit was a no access visit.

3.2.76 The Physiotherapist visited to complete the CAF. Child R was noted to be climbing and walking with a push along toy. Following on from the CAF the physiotherapist and support worker carried out a joint home visit. Adult B raised concerns regards Child R's slow progress with mobility. The dietician was said to be concerned Child R remained on a sloppy diet and was not having finger foods, a decision was made to await the result of sleep studies, Adult B was yet to visit B Hub regarding a nursery placement. It was felt Child R would benefit from play/nursery. All professionals known to be involved were notified of the support workers role as designated key worker.

3.2.77 Feed pump training was arranged for Adult B. Child R's Peg end breaks. Child R's ophthalmology appointment was attended with a plan for on-going review.

3.2.78 Following the allocation of a key worker there was a flurry of activity, the key worker visited the home and discussed nursery placement. A visit arranged for September was attended and Adult B agreed to the placement. A professionals meeting was held, a plan for introduction visits to nursery was formed and a referral for feeding team input made. A 2-year funding application was completed and agreed. Child R was seen by a senior registrar in community paediatrics. Developmental delay was noted and a plan formulated for coordinated care with education and therapies. Child R was referred to the child development forum. A travel voucher application was completed.

3.2.79 Child R had a further admission with a central line infection – his weight was 10.3 kg; this admission delayed Child R's sleep study and attendance at nursery with the key worker.

October 2014 – December 2014

3.2.80 The Physiotherapist continued to visit Adult B at home. Adult B reported the sleep study was complete. Child R was referred for a feeding assessment.

3.2.81 The Key worker started to co-ordinate Child R's care. The CCNs attended nursery to deliver gastrostomy and Hickman line training; Child R was not yet attending and his placement was on hold until after half term so training was cancelled. Adult B subsequently declined the nursery placement stating it was too far; an alternate nursery placement was sought.

3.2.82 Adult B's competence to take bloods, administer PN and IV antibiotics was assessed by SPNPN. Child R was re-referred to SALT by SPN PN this equates to an eight month delay.

3.2.83 Child R was reviewed by gastroenterology. The ENT sleep study was reported normal. Child R was said to choke on food so a further SALT referral was made to the feeding team.

3.2.84 Adult B reported Child R was tired and dehydrated by his third night off PN, and was advised to give dioralyte on the 3rd night. Child R's medication was increased to control stool frequency. It appears Metronidazole may not have been being given frequently enough. On one occasion Child R had a floppy episode following TPN, he was reviewed and his regime changed.

3.2.85 There are a number of days when Child A and Child B were absent from school during this period Child A had 3 days' absence and Child B had 5 days' absence, on occasions no reason was given.

3.2.86 Child R was seen in Paediatric clinic but missed his SALT appointment. At a dietetic review he appeared to have lost weight, his stools had increased in volume (more watery). A further change was made to his diet.

3.2.87 There was one missed and one rearranged appointment with key worker.

3.2.88 Child R was seen by ENT and referred to SALT for video fluoroscopy due to choking.

3.2.89 At the child development forum meeting, Child R's needs were discussed and plans made for support. No actions were identified for the HV at this point.

3.2.90 Adult B attended a viewing of nursery 2 with a plan for Child R to commence in January. The physiotherapist continued to visit regularly and carried out a successful opportunistic visit, Child R was reported unwell. Child R was later admitted with a raised temperature, believed to be an Upper Respiratory Tract Infection (URTI), and given antibiotics.

January 2015 – March 2015

3.2.91 Adult B indicated she would like Child R to start nursery. As a result, a transition meeting was arranged. The meeting took place and as a result the key worker made telephone calls to try and kick start nursery attendance and staff training.

3.2.92 Child A and Child B continued to have occasional one day absences from school.

3.2.93 A family service planning meeting was held. Child R was not gaining weight despite TPN 3 nights a week and bolus feeds alternate days. Child R was having frequent stools and reflux; Child R was referred to pre-school Occupational Therapy for assessment of support for functionality.

3.2.94 Child R had a planned admission for bloods, weight and dietary review. Weight 11.05kg, gut de-contamination continued.

3.2.95 A routine home visit was made by the SPN PN.

3.2.96 Child R had a Gastroenterology admission for growth assessment (weight 11.1kg) and bloods.

3.2.97 The key worker reminded Adult B re a SALT appointment Adult B later stated SALT advised her Child R could swallow normally but could not chew normally. Adult B was given advice and an arrangement was made for Child R to be reviewed 2 months later.

3.2.98 Child R started nursery, his attendance was sporadic but he was settling well. Staff received training. Child R then missed two weeks of nursery sessions, Adult B stated he was unwell when off his PN, and not well enough to attend.

3.2.99 The housing repair inspector attended to inspect damp and black mould in the dining room and bedrooms and a shower hose. As a result, a vent was replaced.

April 2015 – June 2015

3.2.100 The Occupational Therapist made a home visit and completed an assessment of functional needs, discussing the suitability of the accommodation, adaptations and housing options. Adult B was given advice on progressing Child R's gross motor skills.

3.2.101 Several attempts were made to train staff at the nursery re delivering gravity feeds and use of the pump. These attempts were thwarted by the children's illness and Adult B indicated Child R's charger wasn't working. Also training regards management of Child R's central line was affected. Child R was seen by the dietician and had gained weight. Adult B was starting to encourage chewing. Child R was again absent from nursery for three weeks – Adult B reported being really busy.

3.2.102 Housing carried out a number of repairs to the external doors, shower and fitted new kitchen units and work tops

3.2.103 Child R was seen by SALT; there was a debate between hospital and community regarding the need for video fluoroscopy, a decision was made that it was not required.

3.2.104 Child R had a planned ward admission for weight and bloods.

3.2.105 The key worker discussed Child R's attendance at nursery with Adult B. Adult B reported difficulties with her father and his partner which she had been sorting. Social workers were involved and it was possible Adult B might become the carer for their children at some point. The key worker contacted the OT and SALT.

3.2.106 Child R returned to nursery after Easter.

3.2.107 The ophthalmology nurse followed up Child R's non-attendance at two appointments.

3.2.108 Child A and B were absent for 1 day no reason was given. A referral was made to EWO regarding their attendance. The parents were invited to panel but did not attend, later the children's attendance improved.

3.2.109 Child R failed to attend a feeding review but was seen in Gastroenterology clinic and said to be making good progress; eating well, walking, having 2 bolus feeds per day and PN. A letter was sent to all the health professionals involved. Metronidazole needed to be administered two weeks on and two weeks off.

Comment:
It appears Metronidazole was not being prescribed by the GP frequently enough to be administered as prescribed –there were a number of months when no prescriptions were issued. It is known that some prescriptions were being issued from secondary/tertiary care so it has been difficult to establish if there is evidence of non-compliance by the parents. An appropriate recommendation has been made to address this issue.
Parents indicate prescriptions were also being given by the Hospital; it remains unclear whether Child R was receiving all his medication

3.2.110 Child R failed to attend a community paediatric appointment; the key professional had been put off from visiting by Adult B because of this appointment. It is not clear if the key professional was informed. Adult B was sent a reminder regarding an appointment with SALT by key worker but still did not attend.

3.2.111 Adult B attended a family service planning meeting which was later uploaded as a CAF review. Adult B reported illness had affected Child R's nursery attendance although she had not sought any assistance. Adult B requested an OT assessment at home. It is unclear why as this had recently been done but may have related to concerns Adult B raised regarding the outdoor and garden areas being unsafe. There was a plan for physiotherapy to review Child R's mobility. The OT arranged a review at the home but there was no one in, the key worker was informed; the nursery visit completed.

3.2.112 SALT emailed the key worker with regards to the importance of the family engaging.

Comment:
There is evidence that Adult B is either struggling to keep on top of all the responsibilities or non-compliant at this time. Discussion regarding Adult B acting as carer for a half sibling would likely have be an additional strain. It is not known if this was considered within Children's Services assessments as it pertains to a child who is not part of this review however Adult B informed the Lead Reviewer this child was subsequently placed with its mother.

July 2015 – September 2015

3.2.113 Prior to the summer holidays Child R's nursery attendance picked up for a couple of weeks, this was followed by 4 weeks of non-attendance. Adult B reported to nursery Child R was unwell with conjunctivitis and a temperature and possible line infection which may need readmission.

3.2.114 Nursery tried to accommodate Adult B's request for afternoon sessions following Adult B reporting difficulties in taking Child R when Child A and Child B were off school.

3.2.115 A further orthoptist appointment was missed so Child R was discharged. The GP was informed of this.

3.2.116 Child R had a routine admission for bloods and weight 11.9kg

3.2.117 Over the summer appointments were missed with the Occupational Therapist (the OT informs the key worker), the Physiotherapist and Community Paediatrics who discharged Child R. On hearing this the key worker informed Community Paediatrics she was trying to coordinate appointments. These missed appointments were not as a result of ill health necessitating admissions.

3.2.118 Child R attended gastroenterology for routine admission bloods and nutritional assessment; his weight had increased to 12.2kg

3.2.119 Occupational therapy and Physiotherapy carried out an assessment. There had been no emergency admissions for a year and Child R was progressing. The assessment indicated there were no concerns regarding the home conditions, Child R was walking holding a rail. Both Child R and Adult B were reported happy. Adult B was making the garden safe. One sibling was present. After the assessment Occupational therapy discharged Child R with a plan. On the same day Child R missed a SALT appointment; the keyworker and paediatrician were informed. The key worker followed this up with Adult B who said she was unaware she had missed so many appointments. Joint appointments were to be arranged between SALT and the community paediatrician with reminders from the key worker.

Comment:
There is evidence that the key worker is proactively starting to co-ordinate appointments from a variety of services, this would have been made easier if she had had full knowledge of all the professionals involved. At this point non-attendance was being shared with the key worker but there was no explicit consideration by any of the professionals involved that this might constitute neglect on Adult B's part. Trust 1 have made an appropriate recommendation regarding training on the use of Graded Care Profile and neglect.

3.2.120 Child R was allocated a new HV as the previous HV had left; failure to attend paediatric appointments was noted. This allocation was after a prolonged period of no HV input.

3.2.121 Child R had a further routine admission for bloods, weight and urine. Child R was reported to be vomiting; domperidone was restarted, however of positive note, his weight had increased to 12.4kg, Child R was noted to have signs and symptoms that may indicate inflamed kidneys and referred for ultrasound.

3.2.122 The referral for a developmental assessment was not accepted by the community paediatrician as there was no family consent received with the referral.

3.2.123 The key worker followed up Child R's discharge from community paediatrics with Adult B and as a result a joint paediatric/feeding team appointment was made.

October 2015

3.2.124 In the weeks before the critical incident Child R attended the joint appointment. Child R was noted to be sociable and smiling. A further family service plan meeting was planned for November; they were awaiting an Educational Health care plan. There was ongoing involvement with SALT, gastroenterology and dietetic support with a plan for follow up by the community paediatrician in six months. The GP was not aware the worker from the Starting Life Well service was the Key Professional.

3.2.125 On the 12.10.15, Child R was admitted to PICU via A&E following a 999 call from Adult B, with collapse, seizures and respiratory distress. Ambulance staff stated Adult B questioned everything they did and on informing her that they needed to use an airway to assist breathing, Adult B stated, she didn't think it was required. There was a short delay in transferring Child R to Hospital because Adult B argued, she wished him to be transferred to Hospital 2. Ambulance staff felt his condition warranted transfer to the nearest hospital, Hospital 1. Once in Hospital Adult B was noted to be anxious, aggressive, angry and loud with erratic behaviour.

Comment:
It is not uncommon to see out of character behaviours in times of great stress however ambulance staff indicated Adult B did not seem to understand how sick Child R was, hence arguing about which Hospital to go to. Parents of children with long term conditions are always told that in emergency situations their child will need to go to the nearest Hospital. This was also notified by the gastroenterology team in a letter to the parents previously.

3.2.126 Child R's blood electrolytes were out of the normal range; glucose was high (80) and sodium levels were also high (177), on admission. Child R was diagnosed with dehydration, severe acidosis and hyperosmolar non-ketotic coma due to high blood sugars, raised sodium levels, acute kidney problems from a fungal infection and subdural haemorrhages were found on both sides of Child R's brain. Adult B indicated there had been a pump failure. Child R was intubated, ventilated and sedated. A decision was made that the pump failure needed to be investigated.

3.2.127 During information gathering Adult B informed staff Adult A was an alcoholic. On the 15.10.15 Adult B commented to staff about home conditions and her own ability to safely administer PN.

Comment:
This is the first time Adult B raised concerns regarding her ability to care safely for Child R's PN. It was also the first time Adult B indicated there were any issues with Adult A. On discussion with Adult B she believes she was referring to her father and not Adult A.

3.2.128 An attempt to allow Child R to breath independently subsequently was unsuccessful leading to him require resuscitation and being placed on the ventilator again.

3.2.129 Concerns regarding the missing pump and Adult B's comments led to the case being escalated on the unit and a referral being made to hospital safeguarding as per hospital procedures. As a result, the hospital safeguarding paediatrician and nurse met with Adult B and took a detailed history.

3.2.130 The following is the history obtained:

> ***Adult A and Adult B had gone out leaving the children in the care of maternal uncle. The couple returned home at 0100. As Adult B had been drinking Adult B decided not to give Child R PN. Child R was reported well the next day and said to be eating well. That evening Adult B connected the PN as usual. At 2am Child R woke crying, Adult B changed him and noted the pump wasn't working. The gastrostomy feed was said to be running normally. At 5am Child R woke with a pain in his head but settled back to sleep. At 8am, Adult B got up leaving Child R to sleep, when Adult B checked on him later he was lying on his side, unresponsive, foaming from the mouth with his eyes staring. Adult B called an ambulance and whilst waiting, reported Child R had a shaking episode.***

3.2.131 That evening, following the meeting the safeguarding team referred the case to the Police and Children's Social Care, some 4 days after admission. The school nurse was informed but didn't communicate this to the school. All the health professionals known, by the staff, to be involved in Child R's care were informed.

Comment:
The reason for delay to children's social care from the time of admission becomes understandable when the whole picture is analysed. Dehydration and altered electrolytes are not an uncommon event in children with short gut syndrome, although not generally to the degree in Child R's case. The paediatric team initially thought Child R's condition was as a result of his medical condition. Concerns gathered momentum as he was not displaying abnormal fluid loss e.g. no diarrhoea or vomiting, and as blood and x-ray results were received. Adult B's behaviours gave cause for concern; she was anxious, aggressive and not happy with the level of sedation wanting Child R to be extubated. Clear explanation from nursing and medical staff did not improve her behaviours, she continued to be very angry, loud and erratic. Adult B states this is a response she exhibits when stressed. When the PN pump was missing and Adult B indicated difficulties in administering PN safely the level of concern increased. The safeguarding team acted swiftly upon hearing the rising concerns, using the meeting with Adult B to order thinking and gain a better understanding of events leading up to Child R's admission. It could be argued an earlier referral and first interview by the police is preferable, but it is important to understand that the first course of medical support is to make the child better. As it was Child R was in a place of safety and with

the emerging information, the situation became clearer and appropriate safeguarding actions were taken. NB It remains important to consider all the children in a family are safeguarded.

3.2.132 A strategy meeting was held the following morning; those present were a social worker, police, paediatrician, and two PICU nurses. No nursery, school or community staff were invited.

Comment:
There is no agreed process for cascading information from the acute hospital through to other agencies unless a case is already being dealt with within TAC/CiN/CP arenas The lack of multi-agency approach to this case meant that the Hospital staff did not have contact details for non- health staff involved with the family. This is of particular significance for the key worker who by this point, had established a professional but friendly relationship with Adult B and who was placed in a difficult situation. The nature of a strategy meeting means it is not unusual to not have all professionals represented initially however it is vital that all professionals are informed at the earliest point of the concerns. Communicating with all the professionals working with the family should have been part of the plan following this meeting. This would normally fall to the allocated social worker/chair; however, the case did not have an allocated social worker at this point. In the absence of an allocated social worker this should have been an explicit task to be allocated. (see section 5.2 Lead Professional)

3.2.133 The Intensivist at the strategy meeting, (not the allocated Paediatrician), concluded that Child R had not had adequate levels of hydration, that his condition had continued for a prolonged period of time; and that his high glucose was likely to have been caused by a substance which had not yet been identified.

3.2.134 The same Intensivist indicated the bleed on Child R's brain was an old bleed that required further investigation. The hospital had requested the PN machine be brought in so the data collected on the machine could be analysed, Adult B stated whilst bringing it in, it had accidentally been left in a taxi.

Comment:
In cases of unexpected death there are clear Rapid Response (CDOP) procedures. These procedures cover cases where a child has died and there are CP concerns or concerns requiring criminal investigation. This raises the question as to whether the parents should have been asked to bring the PN machine in i.e. contamination of evidence etc. however, in this situation it is difficult to see how, at point of admission, staff could have foreseen Child Protection concerns and acted any differently.

3.2.135 Those present were informed Adult A and Adult B were to be arrested.

3.2.136 Adult B and Adult A were later arrested in front of Child A and Child B. Adult B later contacted the Starting Life Well key worker distressed. The key worker was subsequently advised not to make further contact with the family by managers.

3.2.137 Children's Services placed Child A and Child B with foster carers subject to a Police Protection Order as no suitable adult was found within the family initially. The same day Adult A was interviewed. Adult A indicated he left everything to Adult B.

3.2.138 Adult B was later interviewed by the police.

3.2.139 The following day the nursery made a routine contact to Adult B for an update and learned of the couples' arrest.

3.2.140 The case was allocated to another social worker two days after the initial strategy meeting who organised the second strategy meeting and made plans to contact other universal services. It is clear this does not happen prior to the second strategy meeting.

3.2.141 A second strategy meeting takes place with hospital staff, police and social worker.

3.2.142 The paediatrician present at this meeting has a different opinion to the intensivist present at the previous meeting, as to the length of dehydration - 4 days not 10, and thinks that the bleed on the brain may have a medical cause rather than a physical cause. The police push for a consensus of the paediatrician and intensivist in relation to the bleeds on Child R's brain. The feeding pump was found at Adult E's home It was thought it had been left with Child A and Child B's bags during the panic of dropping them off and was now believed a genuine mistake.

Comment:
The request for consensus of opinion is not unusual. Between strategy meeting 1 and 2 the presenting information changes as the pump, that was worryingly missing, is found but also the Clinician's stance changes. It is not unusual for different Paediatricians/Paediatric staff to have different opinions based on their knowledge and experience, also the passage of time and presentation of new information means clinicians will review and revise their opinions as more test results and information are received, and dependent on the speed of recovery of the child. For social workers and the police, this can be particularly problematic, as they are trying to build a clear picture of the concerns, likely causes and gain clarity on whether there are grounds for concern, a criminal case or potential prosecution. A medical professional can only give information or raise concerns when they have information that justifies their suspicions, thus safeguarding can only progress when all concerns are justified. Within the learning event it became clear that within the hospital records the Doctors were ordering their thinking and writing down the possible causes for the symptoms they were seeing. It would be good practice for all the possible causes to be shared in full with the social workers and police when safeguarding, as a cause of the clinical presentation, is considered. In this case an intensivist and a Paediatrician, who was also a Tertiary Safeguarding Lead and involved for their specific expertise, worked together. As information emerged it informed further decisions and lead to the Safeguarding referral.

3.2.143 On 20.10.15 school were informed by SW 2, that Child A and Child B had been placed in care. Child R was extubated.

3.2.144 On the 21.10.15 Child A and Child B undergo safeguarding medicals; no concerning factors were found although both children were found to be overweight (BMI's were high). This can be an indicator of neglect.

3.2.145 On the 22.10.15 the first legal planning meeting was held.

3.2.146 On the 23.10.15 there was an update regarding the position. The feed pump had been analysed. Feeds had not been administered as prescribed over the previous 2 weeks with a deficit of 2533 mls. Child R went 36-40 hours without PN then Adult B pumped the fluid through at an increased rate. The brain haemorrhages could have been present for weeks, months or even years; there was no cause of the haemorrhages identified. The Police opinion was there was clear neglect and proposed a challenge interview, to be held on 05.11.15.

4 ANALYSIS OF THE KEY ISSUES

4.1 Introduction

4.1.1 Child R's health is a significant factor within this review and as such it is crucial to remain mindful of this as we analyse the key issues. Child R's health issues arose as a result of his medical diagnosis (see section 2.3). In addition, Child R had the added element of prematurity, adding to the complex picture.

4.1.2 Adult A and Adult B's experiences of complex health issues/disability prior to Child R's admission were limited, neither had significant health care issues meaning their experiences of hospitals was limited. Adult A informed the Lead Reviewer he had experienced the cot death of his younger sibling. Their first experience of acute hospital admissions in their family was following the admission of Child B with meningococcal sepsis aged 15 months.

4.1.3 Adult B was seen by the professionals as Child R's carer, with Adult A taking a less active role. The reasons for this stance were not known to, or explored by, professionals. Adult A informed the Lead Reviewer loss of his sibling, the size of Child R, concerns Child R might die and the tubes frightened him to a point that he backed away from that aspect of Child R's care.

Recommendation 1:
All health professionals when taking initial histories should, in addition to obtaining the child's medical history explore a family's previous experiences of health, as well as the family composition, the support network available for the family and parent/s and other needs of the family in relation to housing, monetary needs, health needs etc. when needed.

4.1.4 Child R's prematurity and Short Gut Syndrome led to a prolonged stay in hospital of eight months and required careful management from a number of different health professionals, both within the hospital and, post discharge, in the community also. Child R's prematurity, meant there was a need to carefully review and monitor his development. It is usual practice that this is done by both primary and secondary care staff.

4.1.5 Child R's short gut syndrome meant he was unable to maintain nutrient and fluid balances with a normal diet. Bowel surgery had left Child R with a loss of intestinal absorptive capacity meaning he could not absorb enough fluids and nutrients from liquids and food to maintain good health. The risks associated with this are malnutrition, diarrhoea and dehydration and these were the issues being addressed by the health professionals.

4.1.6 Child R was prescribed medications to treat his short gut syndrome including antibiotics and anti-fungals. Some prescribing was done within the Hospital and some by the GP.

4.1.7 Child R also underwent further surgery to prevent blockage and preserve the length of his small intestine as well as a gastrostomy and PEG insertion to provide a route to deliver nutrition.

4.1.8 This following sections will address the key focus points posed for this review.

4.2 How do we better understand the needs of children with disabilities as a multi-agency group?

4.2.1 In order to better understand the needs of children with disabilities the multi-agency group first need to recognise when a child has a disability.

4.2.2 If a child has been diagnosed with an illness, disability or sensory impairment that needs additional support for them to live their daily lives, they might be described as having "complex needs". This could certainly apply to Child R whose care needs, in the main, related to nutrition, feeding, weight gain and development.

4.2.3 Practitioners at the learning events had differing opinions as to whether Child R fitted the criteria for complex needs or that of a disabled child.

4.2.4 A definition of disability is as follows: *Disability is an impairment that may be physical, cognitive, intellectual, mental, sensory, developmental or some combination of these that results in restrictions on an individual's ability to participate in what is considered "normal" in their everyday society. A disability may be present from birth or occur during a person's lifetime.*

4.2.5 Approximately a fifth of those in attendance indicated they thought Child R was disabled, a fifth believed he was 'normal' (this was largely practitioners working with Child A and Child B) and three fifths viewed him as a child with complex health needs and not disabled. There was no consensus of opinion. This is likely because they did not have all the information on the needs of the child and family.

4.2.6 The requirement for daily Parenteral Nutrition is one of the markers that defines someone with short gut syndrome as disabled. So in effect Child R had both complex health needs and a disability.

4.2.7 The way a child is perceived by professionals is important and becomes relevant when we consider that all are disabled children are considered 'Children in Need' under the Children Act[8]. This brings with it a duty to work within the legislative framework making it much clearer that when a parent does not engage or for example, consent to a CAF the child's needs as potentially a Child in Need must be given the highest consideration.

[8] Children Act 1989

4.2.8 Child R spent his first eight months in hospital. In line with the Children Act the Health Authority seemingly notified the Local Authority, when Child R had been living in healthcare accommodation for three months. The action the Local Authority took on receipt of this notification, was to note it on the Child Disability Register. There is no indication that an assessment of need was considered or carried out at this time. Children with long-term illness and impairment are 'children in need' under the Act and as such are entitled to an assessment of need. Good practice suggests appropriate services and support should be offered to meet any needs identified at the earliest opportunity.

Recommendation 2:
The SSCB in conjunction with the Regional network and its partners needs to ensure all its procedures and training includes complex health issues when relating to disability.
Recommendation 3:

All Section 85 notifications of prolonged admissions to hospital of a child with a disability or with a complex chronic health condition should lead to an assessment of need by the Local Authority. (see section 5.1.6).

4.3 How can we create stronger multi-agency systems to identify and intervene in situations of neglect, particularly if we are working across borough boundaries?

4.3.1 In this case neglect was not given sufficient consideration by any of the professionals involved with Child A, Child B or Child R. There was a mixed picture of compliance with appointments with Adult B seemingly prioritising some appointments above others. Until the allocation of a key worker, professionals were unwittingly making appointments that overlapped each other and in effect making it difficult for Adult B to be fully compliant. That said parents do need to notify the professional of appointment clashes. Whilst the unification of patient centre system in Salford Royal Foundation Trust means all Salford Health Appointments are on one system and can be viewed by the Trusts' employees, thus making it possible to be more accommodating, there remain issues to co-ordinate appointments offered by other organisations e.g. housing and tertiary services.

4.3.2 When individual staff members raised concerns that their appointments were not being attended, others were not experiencing the same issue and therefore the level of concern never reached a threshold where any one individual felt the need to escalate or refer Child R as a Child in Need.

4.3.3 There was a degree of sympathetic understanding applied by the professionals involved, regarding the pressures on Adult B in her caring role. Whilst this is commendable this unwittingly took the professional focus from Child R's needs to the parents, and led to a child with known medical and developmental problems missing routine developmental checks. As a consequence, a proactive approach with involvement of early support services to ensure Child R reached his potential was replaced with a reactive approach.

4.3.4 This is not a new phenomenon and has been a finding in serious case reviews over the last decade.

4.3.5 There remains a need for appropriate communication between various agencies—e.g. tertiary services with primary and secondary services, appropriate notification of actions required e.g. GP was expected to take actions but was not specifically informed what was required.

4.3.6

Recommendation 4:

SSCB health partners need to ensure multiagency participation is an explicit requirement at discharge planning meetings where a child has complex health needs or a disability. This involvement must commence early from the onset of condition so a Lead Professional is allocated to the child and family at the earliest point.

4.4 Parental engagement appears to be minimal. Were the parent's needs overlooked? What counselling and support is available for parents with a disabled child?

4.4.1 This couple were not unusual in not being forthcoming about their relationship, family circumstances and needs. They were also not unusual in their division of responsibilities for child care where there is often one parent who is more active/proactive than the other. Adult A abdicated significant responsibility for Child R's additional cares to Adult B and whilst involved in Child A and Child B's lives it was not fully understood how 'hands on' Adult A was in their day to day cares other than his role in taking and fetching them from school. Adult A indicated to the lead reviewer he perceived himself to have a normal parenting role with all the children.

4.4.2 In terms of Adult B there is a mixed picture with regards to engagement, ranging from Gastroenterology Services who saw Adult B as very engaged, through to SALT and the Community Paediatrician who experienced very poor engagement. This mixed picture related in part to Adult B prioritising Child R's significant medical health needs and not perceiving Child R as having any significant additional developmental needs. There were additional issues with non-receipt of appointments due to a systems issue and changes in address.

4.4.3 The parent's experiences of Local Authority care and the Child Protection system influenced their willingness to seek additional support or engage fully in assessment processes. Adult B told the lead reviewer she had an overriding desire to prove herself as a 'good parent'. This, coupled with Adult B's desire to prove herself capable without Children's Social Care involvement, ultimately presented barriers to the couple having their own needs met.

4.4.4 The support group 'Small Bowel Friends' for those with small bowel syndrome was offered but rejected by Adult B. Adult B indicated they perceived they were discouraged from writing a full account of their experiences, which were not wholly positive, and thus chose to communicate on a social networking site with other parents of children with the condition.

4.4.5 Counselling and support services, professionals report, are not plentiful across Salford with no specific service for parents. All counselling is reported to be of a generic nature accessed via the GP. In this case, neither was sought by Adult B during the review period. At times when Adult B did indicate she was struggling, professionals appeared to relate this mainly to the practicalities of caring for Child R rather than the emotional and physical toll of her caring role. The lack of services served to prevent professionals considering this as an option.

Recommendation 5:

The SSCB partners need to develop pathways for counselling and support provision and ensure the level of service meets the population need and the needs of parents and carers of children with complex health needs and/or disabilities across Salford.

4.5 How can practitioners work together in a manner which takes account of a family's needs, yet keeps children's needs as the focus of intervention?

4.5.1 This case is not unique and raises many of the common professional dilemmas faced by practitioners supporting a family where there is a child with complex health needs. There is the tension about whether to focus primarily on providing support to the family, so the parents are better able to care for their children or move into more assertive intervention.

4.5.2 In this case, the lack of a multi-agency co-ordinated approach inhibited practitioners from working together, and prevented them from identifying concerns and focusing on the needs of the family and most importantly on the needs of Child R. It is not unusual for one agency to have a higher degree of involvement with a child than another, and in these cases professionals can be unwittingly channelled into thinking only in terms of their agency's remit; in this case health.

4.5.3 In the longer term, this is not in the best interests of the child, therefore it is essential that a multi-agency approach becomes standard practice from point of diagnosis so all the child and family's needs can be identified and strategies put in place to address them

4.5.4 For some of the professionals, and for the parents, there was the back drop of the parents bringing legal action against a health Trust This undoubtedly affected the working relationships between professionals and the parents creating a barrier to open dialogue and a reluctance to challenge on the professional's part. This did not lead to consideration of the need for discussion in safeguarding supervision.

4.5.5 Adult B initially refused a CAF and would challenge professionals when she did not agree with a proposed treatment or intervention. In such circumstances the tensions for professionals is between supporting the parents to help them understand the need to follow health advice, balanced with a need to safeguard the child's welfare. Whilst professionals strive to accomplish both, the balance between support for the parents and protection of the child can be difficult.

4.5.6 In this case, there was little consideration as to whether the overall care provided to Child R might be deemed as neglectful of their medical or developmental needs. It can be difficult for professionals to judge this when a parent is seen to do their best to provide their children with a good standard of care and attention.

4.5.7 Safeguarding concerns for disabled children can arise in a number of ways. One way, as in this case, arises from parents being unwilling or unable to follow medical and allied health professional advice and there are consequent potential impacts on the children's health and/or development. This can occur when children are receiving a good standard of care in other aspects of their lives. There were indicators that Adult B was not managing and latterly she requested better co-ordination of appointments to make it more manageable. A multi-agency approach would have met that need and ensured all professionals shared their concerns; had they been, the focus may have moved and led professionals to consider moving into explicit child protection processes.

4.6 What are the challenges to identifying matters of neglect when working with complex health situations across many health providers?

4.6.1 There are many challenges to identifying neglect when working with complex health cases across many health providers. One of the biggest challenges is around communication. Maintaining communication across disciplines when electronic systems are not compatible and individuals cannot readily access other professional's records, whilst essential, is challenging. This becomes increasingly complicated as patients are referred on to new services and discharged from others.

4.6.2 Only by having a single point of contact, (in effect a Lead Professional) trained to understand the indicators of neglect of sufficient seniority to act with authority, which holds all the information for a child, can professionals have a degree of assurance that issues of neglect can be identified (see section 4.8). In this case there was no Lead Professional.

4.6.3 Medical staff at Hospital 3 believed that there was an agreement that the GP should be the person who receive all the information pertaining to a child's treatment and admissions and take action. In part this is correct and guidance for doctors[9] indicates "you must consider the safety and welfare of children and young people, whether or not you routinely see them as patients." Whilst GP's hold the comprehensive medical records and take action if concerns emerge, it is essential that any actions required by tertiary providers of GP's are clearly requested.

4.6.4 In this case there was very little direct contact between the GP and Child R (two appointments) however information in the form of discharge letters, notification of non-attendance and changes required to prescriptions was, on the whole, shared with the GP. There is no evidence that any one GP was reviewing the case and that non-attendance with other services was considered by the GP practice as an indicator of neglect or required them to take any action taken. The GP did however follow up non-attendance to an arranged appointment at the GP practice.

4.6.5 Changes to the National GP contract mean that all patients now have an accountable GP; for Child R allocation occurred in June 2015. Following allocation, Child R was not seen in the GP practice, however information was still being shared by the Hospital.

4.6.6 The lack of a system to identify that insufficient prescriptions were being requested by the parents for medication required by Child R to treat his condition, meant the GP did not recognise a further indicator of neglect, non-compliance with treatment. It is essential there is effective communication from hospitals to GPs when they give prescriptions, along with specific notifications of actions to be carried out by GP. There are many occasions currently, when GPs are not aware of prescriptions given by hospital services especially if children visit hospitals frequently as in this case, thus making it difficult for GPs to know when to prescribe. An appropriate single agency recommendation to address this has been made.

4.6.7 Whilst Hospital 3 were routinely sharing information with the GP other services were not. For example, the GP received no information from Health Visiting or School Nursing. In Salford now, there is communication between HV teams and GP surgeries on patients with complex needs, at the GP surgery meetings, where children's needs and concerns can be discussed. The HV and SN's are now part of one integrated team and whilst the SN's do not meet with the GPs HV's will take GPs concerns back to the SN's.

[9] GMC. Protecting Children and Young People: The responsibilities of all doctors (2012).

4.6.8 Another challenge is around roles and responsibilities. Within safeguarding there is clarity around individual practitioner's responsibilities to safeguard a child, however when there are numerous professionals involved with a child, it is not unusual for that clarity to become blurred, as junior staff may defer to seniority in decision making and 'group think' can stop professionals acting appropriately.

4.6.9 Clarity about the roles, inclusion of safeguarding professionals to facilitate supervision to professionals involved in these complex cases, providing objectivity and challenge is essential.

4.6.10 In this case no supervision was sought by any of the professionals involved in the case and there was no involvement of health safeguarding professionals until after the significant event.

Recommendation 6:
SSCB to ensure that policies set an expectation that professionals working with complex child health cases and those where there are barriers to open dialogue and challenge discuss this in safeguarding supervision and ensure concerns are shared with lead professionals, and that CAF guidance provides consistent advice that links to the 'threshold of need' and 'Uncooperative families' Greater Manchester policy.

4.7 Should only one parent be trained to administer Parenteral Nutrition feeds?

4.7.1 Within the learning event there was much debate about this question. Practitioners who work within the specialism believed this was acceptable if not ideal. In this case Child R, at the point of discharge from hospital, was on PN five nights a week. This gave a degree of flexibility to Adult B regarding which nights she chose to administer this.

4.7.2 In effect, if Adult B was unwell or indeed planned to be away for a night, Child R could still receive his prescribed nutrition over the course of a week.

4.7.3 There are parents who administer PN who are single parents, and to say there needs to be more than one parent trained to administer it, would delay the discharge causing unnecessary prolonged hospitalisation.

4.7.4 The question would appear to centre around the support needs of the parent in order to be able to consistently and safely administer PN and also meet Child R's wider needs. Best practice would be for two people to be trained, the second could be a grandparent or aunt or a sister or brother of the parent who is local as illness in the mother not requiring hospitalisation would compromise the safeguards for the child. Indeed, a requirement from the final court hearing-is to train Adult A.

4.7.5 In this case the issues were wider than administering PN. Feeding and weight gain were managed and monitored in the main by Adult B and the gastroenterology team. Child R received his nutrition in three ways. The first was orally through a combination oral rehydration often in the form of dioralyte, which provides the electrolytes required, and latterly through finger foods. Child R was not able to maintain growth and nutrition via oral feeds and so received a combination of parenteral nutrition (PN) with fluids, electrolytes, liquid vitamins and minerals going into the bloodstream through an intravenous (IV) tube or central line and enteral nutrition with food to the stomach through a feeding tube. Health care providers usually administer parenteral and enteral nutrition in the hospital setting; however, where this is required long term it is usual for family members to be trained to administer this; there was significant involvement with a specialist nurse who supported Adult B in both the hospital and community.

4.7.6 Adult B was consistently the main carer for Child R and was frequently resident and, if not, a daily visitor to Child R whilst he was in Hospital. Adult B had undergone training in order to be proficient in recognising any complications of Child R's condition and in carrying out Child R's cares. This role brings with it considerable responsibility and changes the dynamics of the parent child relationship.

4.7.7 Child R had numerous re-admissions following initial discharge. Some of these were for continuation of treatment through surgery and some were as emergencies when Adult B indicated a concern regarding Child R's general wellbeing, predominantly when he was pyrexial. On no occasion were any of those admissions deemed unnecessary, which indicated to staff, that Adult B largely understood the circumstances which warranted admission.

4.7.8 On most of these occasions Child R was found to have a central line infection. Whilst line infections are a potential side effect with all intravenous lines; research shows, in patients receiving parenteral nutrition (PN), Candida albicans and non-albicans Candida and Malassezia furfur have been found to be common causes of IV line infection. Researchers looking at the incidence of line infections found that home intravenous therapy resulted in fewer infections than with hospital care, 10 and so such frequent line infections caused health professionals to be concerned regarding Adult B's competence. Latterly this was checked in the family home and Adult B assessed as competent.

4.7.9 Adult B did not always agree with professionals on the best course of treatment for Child R and it was reported at the practitioners' events, would challenge professionals, if she disagreed with a proposed course of action, on two occasions rejecting admission. There were some concerns regarding Adult B's compliance with treatment within secondary/tertiary care although these were not documented or widely shared nor did professionals escalate any of their concerns.

[10] Cunha, Burke A. "Intravenous line infections." *Critical care clinics* 14.2 (1998): 339-346.

4.7.10 All parents receive extensive training and assessments are made of both competence and the home environment.

4.7.11 In this case Adult B was deemed competent on all occasions this was assessed. There was an issue regarding maintaining an environment where Adult B could give her undivided attention to her task. Attempts made to address this included encouraging Adult A to keep Child A and Child B from the room whilst Adult B set up the PN.

4.7.12 Adult B's knowledge of, and competence in, managing Child R's TPN gave professional (both health and non-health) a positive impression and she was viewed not only as a parent but as an expert in Child R's care.

4.7.13 These professionals did not know that there had been concerns that Adult B was prone to outbursts and could be confrontational in her challenge of professionals if she didn't agree with what was proposed, raising her voice and invading personal space and that, at times this had impacted on treatment, for example only receiving two days of antibiotics when prescribed seven. When challenged, Adult B learned, but at that stage the treatment had already been missed. Adult B also formed strong opinions of professionals, questioning the competence of some.

4.8 Given the complexity of the case, was consideration given to appointing a Lead Professional at a sufficiently early point? Was consideration given as to which practitioner was the most appropriate Lead Professional? Was there confusion about the existence of or identity of the Lead Professional and the functions of the role?

4.8.1 In this case the simple answer to all the questions posed above is no. It is now clear that there was no Lead Professional at any point during the period under review. The community Physiotherapist took on some of the role of a Lead Professional between Child R's discharge and September 2014 when, following completion of the CAF an Early support key worker from the Starting Life Well service was allocated.

4.8.2 The key worker attempted with some success to co-ordinate appointments and fulfil some of the functions of the Lead Professional. Indeed, there were some professionals who referred to the key worker as Lead Professional. The lack of a Lead Professional is a fundamental issue within this case and a key finding – see section 5.

4.9 Was consideration given to holding a Team Around the Family (TAF) meeting to formulate plans and implement them?

4.9.1 In this case no consideration was given to holding a team around the family meeting prior to the critical incident. There were a number of issues that could also have led to CAF and ultimately a TAF. Initial refusal of CAF appears to have impacted on professionals considering offering this again.

Housing issues

4.9.2 Housing had a rather different role with the family to any of the other professionals and a very different perception regarding the structure of the family. Housing's information led them to believe that Adult B was a single parent of three children; they had no knowledge of Adult A.

4.9.3 The family were experiencing significant change in relation to housing during Child R's initial hospitalisation with a requirement to vacate their home, declaring themselves homeless and then moving into bed and breakfast accommodation before moving to more permanent accommodation. Whilst staff on the ward were made aware of these issues initially, and wrote supporting letters providing information to housing that was helpful, there was no further communication between housing and other agencies with regard to the timing of these changes and rent arrears which continued for a further two years.

4.9.4 Following the critical incident Adult B indicated the conditions at the house were impacting on her ability to safely administer Child R's PN, a concern that had not been voiced, to either health professionals or housing, previously. The full impact of the housing issues on the family and whether this inhibited Adult B from voicing concerns at an earlier stage remains unknown.

School absenteeism

4.9.5 Child A and Child B had intermittent periods when their school attendance was of concern. The EWO became involved at these times, following their normal processes and procedures. It was reported by school that Child R's health was known to be having some impact on his siblings' school attendance but the parents' failure to attend panel meetings, refusal of CAF and an improvement of the children's attendance meant there was no recognised need for further intervention.

Comment:
Whilst there was discussion between School and EWO regarding Child R's health impacting on Child A and Child B's schooling, there was no discussion between the school and any health professional to look at preventative strategies should Child R's health deteriorate.

Recommendation 7:
A system needs to develop whereby Health Visitors working with children with complex needs/disabilities, who have school age siblings, are required to inform the appropriate school nurse.

4.9.6 Following completion of a CAF and referral by the Physiotherapist, an Early Support key worker from the Starting Life Well service was allocated. Following this, family service planning meetings took place, looking specifically at Child R's health needs. Whilst these meetings brought a degree of co-ordination to services in the community, there was no involvement of secondary and tertiary care professionals or the GP, inhibiting information flow and effective planning. This was not sufficiently recognised by those in attendance at that time.

4.9.7 The needs of the whole family were not explicitly discussed within these meetings however the meetings were in their infancy and there was a plan for a further meeting in November after the critical incident.

4.10 Is there evidence of escalation of concerns by any of the practitioners who felt at points that child protection processes should have been initiated? Was there over reliance on medical consensus in initiating child protection procedures?

4.10.1 In this case none of the practitioners involved considered there were sufficient concerns to initiate the use of child protection processes until after the critical incident.

4.10.2 CAF was considered by Child A and Child B's school however, following advice from Children's Social Care, as an initial assessment was being undertaken they were advised it was not necessary. Across Salford CAFASS Assessments are not being shared thus limiting professional's abilities to challenge the assessment or escalate their concerns.

Recommendation 8
Children Services to consider how CAFASS assessments can be shared across relevant partner agencies and with parents.

4.10.3 At the point of the critical incident the concerns were appropriately escalated to the named safeguarding professionals within the Trust. An appropriate response was made, leading to referral to Children's Social Care and the Police.

4.10.4 Following on from the referral, the case followed a recognisable route into Child Protection investigation and legal processes.

4.10.5 In those first days, following admission, there was considerable activity for all the professionals involved directly in caring for Child R, his siblings and in the arrest of his parents. What is apparent, is the lack of central co-ordination, to ensure that all professionals involved with the family are notified at the earliest point.

Comment:

If there had been a Lead Professional this would likely have been their role however,

in the absence of a Lead professional, it remains imperative that notification is received immediately by professionals to prevent them from unwittingly contacting the family or being placed in compromising situations when contact is made. This would normally be addressed at the strategy meeting. An action plan would normally be agreed which should identify actions and practitioners responsible for these actions.
Recommendation 9: *It should become routine practice that the Children's social care representative in attendance at the strategy meeting informs the Lead Professional regarding serious incidents in order they can inform all the professionals involved. Guidance needs to be developed to address this. See Recommendation 12 & 13.*

4.10.6 In terms of offering protection to the children, there is no evidence that there was over reliance on medical consensus in initiating child protection procedures. The impact was seen when the Police were trying to progress the case and make decisions regarding the grounds for arrest.

5 FINDINGS & RECOMMENDATIONS

5.1 Introduction

- This chapter contains the overall conclusions and findings of this serious case review, with additional associated recommendations for the SSCB. The findings relate to what we have learnt about the strengths and weaknesses in multi-agency safeguarding systems.
- The findings of the recommendations of the individual agencies SARs are included as an appendix (see appendix 1). The SSCB has prepared a separate document with their responses to these findings and the plans to address the recommendations.

5.2 Findings and associated recommendations

The complexity of Child R's health needs overshadowed his developmental needs and inhibited staff from recognising Child R as a child with disabilities

5.2.1 The majority of the focus of both professionals and Adult B was on Child R's health needs, whilst this is somewhat understandable, Child R's developmental progress was infrequently assessed by Professionals. Adult B alternately was/wasn't happy with his development.

5.2.2 Recognition should have followed notification to the LA of Child R's prolonged stay in Hospital. Section 85 of the 1989 Children Act places a duty on local authorities to check on the safety and welfare of children living in hospital provision for any continuous period exceeding and/or likely to exceed 12 weeks.

5.2.3 The intention behind the legislation is to provide a 'safety net' for vulnerable children living away from home where the child is not accommodated under section 20 and where the child is not subject to the usual processes of care planning and review by and Independent Reviewing Officer.

5.2.4 The legislation is aimed particularly at ensuring the safety and support needs of disabled children and their families. It is well recognised that these children are at increased risk of significant harm within every category of abuse due to their increased level of dependency on others. The families of disabled children also experience enormous demands upon their parenting capacity in trying to meet a child's additional needs.

5.2.5 The Children and Young Persons Act 2008 amends Schedule 2 Part 1 of the 1989 Children Act and clarifies the sort of services appropriate for 'accommodated' children away from home (Section 85) including financial help to promote contact, advice, counselling and help for children to holiday with their family as well as the provision of advocacy services.

Recommendation 10:
Local Authority to review the current practice regarding children living in hospital provision (Section 85 notifications) and provide an assurance report to the SSCB regarding how robust the process is.

5.2.6 Secondary and tertiary health services delivered their services in an appropriate manner. There was however gaps between these services and those within primary care provision with some impact on the services offered by the Community Paediatrician, Health Visiting, the GP and Community Nursing. The reviewer learned that referrals to community services initiated by tertiary hospital staff are made through a cascade system. For example, the Health Visitor was tasked with making a referral to the local Community Paediatrician. This system adds another layer in the referral system and relies on individuals referring issues they have no ownership for, causing the reviewer to question whether this model is robust. The process between services in Salford is robust. GPs refer on the choose and book system, health visitors, school nurses, allied health professionals e.g. speech therapy, audiology etc. refer on the electronic referral form that is triaged on a daily or every other day basis in Paediatrics. In this case referral was delayed.

5.2.7 It is usual for Community Paediatricians to have a role in caring for a child with complex health needs and disabilities in the community so it is surprising that a referral to this service was not initiated by local health staff.

Recommendation 11:
SSCB health partners to agree a process to ensure all children with ongoing complex health and developmental needs are referred to community Paediatricians before discharge from secondary/tertiary hospitals with information of the child and the likely issues that may need supporting.

5.2.8 The Healthy Child Programme provides guidance to health visitors and school nurses who are commissioned to deliver their services in line with the programme. Child R was being seen by a Health Visitor fairly consistently over the first two years of life, and as a minimum should have had a nine month (recent guidance does not include this assessment as statutory) and a two-year developmental assessment as part of that programme. It has not been possible to establish what impacted the completion of these assessments, save to say they would have provided a baseline on which Child R's progress could be measured over the following months, and thus ensure provision of information to influence service involvement and delivery.

5.3 Common Assessment Framework[11]

5.3.1 Consideration was given to the need for a CAF to be completed on a number of occasions and by different agencies. CAF is a voluntary process, hence in order for a CAF to be completed there needs to be consent from a parent. On occasions when this was muted, Adult B refused consent. Practitioners indicated, they believed that Adult A and Adult B's experiences of being in care and of the involvement of child protection services when Child A was subject to a child protection plan, had impacted. Adult B confirmed a desire to prove she could care for her children without children's services involvement. This, coupled with the parents' belief this CAF was part of Child Protection, lay behind the lack of consent.

5.3.2 Without a CAF, a TAC could not be held. If the CAF had been completed it would likely have concluded that a multi-agency response was required, and a TAC would have been formed and a delivery plan agreed by the TAC members.

5.3.3 When CAF was refused there was no consideration of the likely impact of this refusal on Child R or the family, or consideration of the need to hold a multi professionals meeting. This is contrary to the SSCB current threshold of need guidance[12] which states, 'Where parents/carers are uncooperative with all agencies there is likely to be a lack of information leading to an incomplete picture of the child and his or her welfare. Under these circumstances the practitioners involved will hold a meeting to decide the level of concern and plan a response to promote the child's welfare.' Guidance can also be found in the Greater Manchester procedures[13] and a Salford guide.[14] This guide indicates that 'When the CAF cannot be completed with the family. Consent can be overridden. If you feel there are safeguarding concerns and the child is at risk of significant harm or likely to be by trying to gain consent'. In contrast the working with resistant families flowchart[15] makes no mention of professional meeting. It is important to recognise this family didn't appear resistant to many professionals however this could have been picked up by a Lead Professional and the above procedures and guidance used in conjunction with the Greater Manchester uncooperative family's policy. See Recommendation 12.

5.4 There lacked a multi-agency network around the family.

[11] A framework to help practitioners working with children, young people and families to assess children and young people's additional needs for earlier, and more effective services, and develop a common understanding of those needs and how to work together to meet them.

[12] http://www.partnersinsalford.org/sscb/Thresholds.htm

[13] http://greatermanchesterscb.proceduresonline.com/chapters/p_deal_uncooperative_fam.html?zoom_highlight=managing

[14] *http://www.salford.gov.uk/media/389141/caf-and-tac-q-and-a-sheet.pdf* **What happens if parents don't consent?**

[15] www.salford.gov.uk/children-and-families/safeguarding-children/advice-for-professionals/caf-and-tac/lead-professional-and-chairing/

5.4.1 This impacted on professionals, Child R and his family. Agencies and professional groups were working in silos, with limited awareness of Child R's condition and care needs. Child A and Child B's school had no knowledge of the complexity of Child R's condition or the impact of this on the family. The lack of a multi-agency forum to share information limited professionals' abilities to understand the issues and concerns, and reduced the potential for professionals to identify and act upon concerns.

5.4.2 It is clear that the lack of co-ordination across services meant there were numerous occasions when Child R's appointments clashed and Adult B was in a position of prioritising which appointment to attend.

5.4.3 The impact of Child R's health needs on Child A and Child B's school attendance is noticeable when all the information is brought together. Multi-agency networking could have helped put in place a helpful support plan when Child R had planned admissions and reduce the impact on both parents and children.

5.4.4 Different recording systems in agencies posed an additional barrier to networking however the proposed introduction of Version 2 of the Salford integrated record is expected to alleviate some of the issues.

5.5 The lack of an allocated Lead Professional impacted both on the co-ordination and delivery of services causing difficulties for both parents, children and professionals

5.5.1 Whenever there are large numbers of professionals working together there will be difficulties in coordination and promoting a united response. The responsibility for co-ordination largely falls to the 'Lead Professional' however in this case this role was not allocated leading to the lack of communication between various teams who were individually supporting Child R.

5.5.2 Latterly, there was a 'key professional' in the form of an early support worker who fulfilled some of the functions of a Lead Professional role and brought about a greater degree of co-ordination. Whilst this was positive, confusion arose through a lack of understanding of the difference between the role of a key professional and a Lead Professional, and the limitations of having a non-health professional at the helm of such a health focussed case.

5.5.3 The lack of Lead Professional tied to the different understandings of the meaning of key worker is worth exploration. Within health, the term 'Lead Professional' is used to refer to the professional most involved in supporting the patient's needs- this could be an allied professional or paediatric consultant (in charge of the patients' health treatment, usually a medical consultant). In this case there were multiple consultants involved in Child R's care however no overarching consultant ever held the case. This often falls, post discharge, to a Community Paediatrician; however, Child R was not referred to the Community Paediatrician until post discharge and because Child R was not brought to appointments the Community Paediatrician had no direct involvement in Child R's care until later.

5.5.4 Within the wider multi-agency environment, the term has a specific meaning. The Lead Professional role[16] is defined in government guidance as 'a set of functions to be carried out as part of the delivery of effective integrated support'. These functions are to:

- 'Act as a single point of contact for the child, young person or family'
- 'Co-ordinate the delivery of the actions agreed by the practitioners involved in the multi-agency TAC to ensure that children, young people and families receive an effective integrated service which is regularly reviewed: these actions will be based on the outcome of the common assessment and recorded in the CAF delivery plan'
- 'Reduce overlap and inconsistency in the services received by children, young people and their families '

5.5.5 Salford's' CAF team have guidance available regarding the above.[17]

5.5.6 The parents did not recognise any one person as the Lead Professional. When Child R became unwell prior to emergency admission, Adult B took steps to provide the deficit from the missed PN but didn't seek medical advice. Adult B indicated to the lead reviewer she had been told to do this on a previous occasion and so believed it the right action to take. There is evidence Adult B had been given clear instructions on what action to take if Child R was unwell by the Gastro team and indeed had previously followed this advice and accessed appropriate treatment. It remains unclear to the Lead Reviewer why Adult B did not follow the instructions given on this occasion; Adult B indicated she had never received a written plan.

[16] The Team around the child (TAC) and the lead professional, Children's Workforce Development Council
[17] http://www.salford.gov.uk/children-and-families/safeguarding-children/advice-for-professionals/caf-and-tac/lead-professional-and-chairing/

5.5.7 Adult B was seen as somewhat obstructive of the Ambulance Service, dictating her wishes rather than following their recommendation.

5.5.8 Part of the multi-agency approach should be to outline strategies and provide a multi-agency plan of action of what to do when a child is unwell which is given to parents, reinforced frequently and monitored. This would ensure clear and consistent direction to parents with the potential to gain evidence of compliance/non-compliance building a picture and identifying cases of neglect.

5.5.9 The role of the Lead Professional is critical in such complex circumstances, but consideration needs to be given to how all the functions of a Lead Professional can be undertaken and who is best placed to fulfil this role.

Recommendation 12
Salford SCB to agree with member agencies a consistent process for identifying the Lead Professional and the responsibility for the various functions of the Lead Professional.

5.5.10 Following Child R's admission in a moribund state and the movement of the case into Child Protection and a criminal investigation the need for clarity amongst all the professionals involved in his care became even greater. Community staff, in particular, including non-health staff were not immediately formally informed of the situation, and in some cases, were informed by Adult B during routine contact, of their arrest. This placed professionals in an extremely difficult situation wanting to support the family whilst not compromising any on-going investigation.

Recommendation 13:
The SSCB, with the support of the Police and Children's Social Care, to develop multi-agency guidance for staff on their engagement with parents during criminal investigations e.g. the. do's and don'ts of discussions regarding their situation.

Incidental Learning falling outside the Terms of Reference

5.5.11 Staff attending the practitioner events expressed concern that the parents were arrested in front of Child A and Child B. Adult A and Adult B confirmed this in interview with the Lead Reviewer, indicating they had been placed in handcuffs in front of the children and expressed their concerns regarding the trauma caused to the children and the ongoing negative impact this has had. The Police and the SSCB will take forward this learning.

6 CONCLUSIONS

6.1.1 Professionals who had been involved in Child R's care or with his family expressed their shock on hearing of Child R's moribund condition and on the arrest of his parents on suspicion of neglect.

6.1.2 Adult B was seen to have a very loving relationship with her children, Child R in particular was always happy to be with her. Adult B demonstrated her commitment to all her children even if at times, she was overstretched or unwilling to accept the support on offer.

6.1.3 Whilst there was nothing to suggest an incident of this nature was likely, issues regarding compliance with treatment had been previously identified. For a child who is as vulnerable as Child R, receiving optimal care is of the highest importance.

6.1.4 Adult B could be very challenging of professionals and it was known to some that she was suing a health Trust, and was documented to have challenged incorrectly the decisions of professionals when Child R was unwell. The impact of this on professionals has been difficult to establish. At the learning event attendees stated Adult B "sounded like a nurse," and there was a ready acceptance of a degree of expertise both within community health practitioners and non-health professionals. It appears this affected professional interactions with Adult B impeding challenge and suggesting a different approach adopted to parents who are thought to be very informative about their child's condition and management.

6.1.5 On the occasions Adult B was challenged about compliance issues, she demonstrated an ability to learn and modify her behaviours. As a result, no one with direct involvement and care of Child R, expected or predicted an incident of this kind. When Child R became unwell prior to emergency admission, Adult B undertook steps to provide the deficit from the missed PN, however, she did so without seeking medical advice. In addition, Adult B challenged the Ambulance Service over their care of Child R, dictating her wishes rather than following their recommendations and the advice given previously by the tertiary hospital. Had Adult B followed the instructions on actions to be taken if Child R was unwell, as on previous occasions, and sought advice, this situation may have either been averted.

6.1.6 The lack of recognition of Child R as disabled, prevented a more multi-agency, holistic approach to assessing and managing Child R within the context of his family. Allocation of a Lead Professional in such a case is essential.

6.1.7 The impact of the lack of an allocated Lead Professional and lack of multi-agency approach cannot be under estimated. In this case it led to a lack of co-ordination and clarity for both professionals and parents, and reduced opportunities for communication between professions and teams. A Lead Professional would have been well placed to reinforce the messages between Professionals and parents and challenge any compliance issues.

Glossary of Terms & Abbreviations

A&E	Accident and Emergency
CAF	Common Assessment Framework
CCN	Children's Community Nurse
CiN	Child in Need
CP	Child Protection
ENT	Ear, Nose and Throat
EWO	Educational Welfare Officer
GP	General Practitioner
HV	Health Visitor
IV	Intra-venous
LA	Local Authority
OT	Occupational Therapist
PEG	Percutaneous endoscopic gastrostomy
PICU	Paediatric Intensive Care Unit
PN	Parenteral Nutrition
PT	Physiotherapist
SALT	Speech and Language Therapy
SGS	Short Gut Syndrome
SPN	Specialist Paediatric Nurse
SSCB	Salford Safeguarding Children Board
TAC	Team Around the Child
TAF	Team Around the Family
TPN	Total Parenteral Nutrition

Appendix 1: Single Agency Recommendations

Salford Royal NHS Foundation Trust

1. Communication pathways will be developed between Nursing and Allied health Professionals.
2. A MARAM lead will be identified for both Universal and Targeted Services.
3. The development of one Electronic Patient Record (EPR)
4. All staff to continue to access safeguarding supervision.
5. All children will have been offered the core element within the Healthy Child Programme.
6. The rational for additional interventions within the core programme will be clearly documented in the records.
7. All relevant staff will be adept in the identification of when a family require a Common Assessment Framework (CAF) to be completed.
8. Weights are recorded in line with the Faltering Weight Guidelines.
9. Implement a "Management of a vacant caseload" policy.

Central Manchester University Hospitals NHS Foundation Trust
Royal Manchester Children's Hospital.

1. From April 2016 CMFT to raise awareness through Level 3 Safeguarding Children Training that parents will not always disclose concerns or issues, however asking a parent how they are coping or if they need help may give them the opportunity to discuss any concerns.
2. From April 16 CMFT Level 3 Safeguarding training will include the need for 'respectful uncertainty' and consider the Lessons from previous serious case reviews nationally highlighting the 'rule of optimism' and professional dangerousness to increase awareness of this issue.
3. Improved documentation in relation to documenting conversations, presentation and the voice of the child will be included in the Record Keeping Audit planned for Quarter 4 in CMFT as part of the safeguarding work plan (Jan – Mar 17)
4. The CMFT Record Keeping Audit in Quarter 4 will include ensuring that all documentation from Specialist Practitioners is included in the main medical records.
5. Level 3 Safeguarding Training highlights the need for closer liaison with Community Practitioners when a child is admitted, in particular those children with a long term medical condition or disability, to ensure robust communication and information sharing and where appropriate there should be identification of a lead professional. This will be audited within the Safeguarding Record Keeping Audit in Quarter 4.

NHS Salford Clinical Commissioning Group

1. Individual GP practices to review the management of cases involving children with complex needs ensuring that the individual child has a Lead Named Accountable GP.
2. Individual GP practices to ensure patient record flagging systems are in place for a complex case that has the potential to be reviewed by several GP's in the same practice. This should include linking family members to children within the practice.
3. Individual GP practices to ensure electronic patient record flagging systems are in place for children who are not brought to appointments (DNA)with a process for review and follow up. This information to be underpinned by a GP Practice Policy for the Management of DNA in Children within Primary Care.
4. The process and system for review of patient medication requests and repeat prescription on GP systems needs to be reviewed so that repeat prescription requests including identifying under ordering of medication as well as over ordering can be identified. This should culminate in closer monitoring and review of medication.

5. Record keeping guidance within GP practice to be refreshed within the safeguarding children training in light of children with complex needs and also discussed at the local NHS Salford GP Safeguarding Leads Forum.
6. Training to be delivered around the lessons learned from this Serious Case Review in practice from a multi-agency perspective to inform current and future practice in Primary Care. This information will also be cascaded by the NHS Salford GP Safeguarding Leads Forum & CCG GP Newsletter.

Salford City Council Children's Services

1. Social Workers and Team Managers must prior to the closure of any case ensure that they identify the most appropriate lead professional i.e. Key Worker to co-ordinate proportionate work with families in need of services. This will in the initial stages be lead by the 0-25 pilot in West. Once this has been evidenced as a positive working model it will then be rolled out to all four areas across the city.
2. Further work from Service Managers in Team Meetings in respect of social workers and managers taking account of historic details and patterns within a Chronology of parents own experiences or episodes. This will inform decision making without being over reliant on the self-reporting of parents' ability to manage without professional intervention.
3. Practice Managers within the Bridge who screen lower level referrals must consider the history prior to agreeing to the BRAG rating of a case before allocation or closure to services. Salford new system will support this but the Head of Service to arrange a training sessions for Practice managers where this issue can be discussed and shared.

Educational Welfare Service

1. All Education Welfare officers will record all interventions and family details including full names of parents/carers and professionals and reflect clearly work undertaken
2. Support given to all Education Welfare Officers to ensure a consistent approach to recording interventions and actions
3. Managers to ensure that communications logs are kept up to date and are SMART
4. A clear indication of pupil attendance at the time of any significant event should be evident

Starting Life Well Service

1. Outline the role of the Early Support Key Worker as lead professional to ensure that professionals are aware of what the role entails
2. Review of family service plan meetings to ensure that if at any stage CAF is required this is completed in tandem with the FSP meetings.

Salix Homes

1. Officers should adopt a consistent way of collating and recording information. Information should be captured in one central place in the organisations Housing Management system and should include 'global' picture of what is known about the family.
2. Salix Homes should review and revise its vulnerable customer alert processes. This review should include better use of flags and alerts for front line staff
3. Salix Homes should use the learning from real life case studies with front line officers to raise awareness and reinforce their safeguarding

Appendix 2: Panel members

The review panel consisted of the following members:

AGENCY	ROLE
	Lead Reviewer
Greater Manchester Fire & Rescue	Chair - Community Safety Manager
CMFT	Named Nurse: Safeguarding Children
Duty & Assessment, Salford Children's Services	Service Manager
Education	Childcare Strategy Manager
GMP	Detective Sergeant
Housing Options	Service Manager Housing Choice and Support
Manchester & Salford Legal Department	Deputy Head of Legal Services
North West Ambulance Service	Safeguarding Practitioner Prevent Training Lead
Public Health	Assistant Director: Public Health Nursing
Salford CCG	Designated Doctor: Safeguarding
Salford CCG	Designated Nurse for Safeguarding Children and LAC
Salford Children's Services	Business Manager, Education Welfare Service
Salford Children's Services	Head of Integrated Social Work & Prevention
Salford Children's Services	Interim Head of Safeguarding
Salford Royal Foundation Trust	Named Nurse Safeguarding Children
Salix Homes	Neighbourhood Manager
SSCB	Interim Business Manager
SSCB	Senior Business Support Officer

Practitioners involved in the SCR process

The following practitioners were involved in individual and group meetings with the lead reviewers and other panel members:

AGENCY	ROLE
CMFT Gastro Nurse Specialist	NMP Nurse Specialist for Paediatric Home Parenteral Nutrition and Inflammatory Bowel Disease
CMFT Department of Paediatric Medicine	General Paediatric Consultant
CMFT Paediatric Intensive Care Unit	Matron
CMFT Paediatric Dietician	Paediatric Dietician
CMFT Safeguarding Team	Named Nurse: Safeguarding
Education Starting Life Well	Early Support Team Leader
Education Primary School	Safeguarding Officer
Education Starting Life Well	Early Support Designated Key Worker
Education Nursery	Nursery manager
Education Nursery	Children's Centre Coordinator
GMP	Detective Sergeant
GMP	Detective Sergeant: Serious Case Review Team
GMP	Officer in Charge
Housing Options	Service Manager - Choice and Support
Housing Provider	Neighbourhood Officer
Housing Provider	
MRI	Consultant Gastroenterologist
NHS Salford, Clinical Commissioning Group	Specialist Nurse: Safeguarding Children
Primary School	Executive Head Teacher
Salford Children's Services Emergency Duty Team	Social Worker
Salford Children's Services	Education Welfare Service

Education Welfare	Manager
Salford Children's Services Education Welfare	Education Welfare Officer
Salford Children's Services Looked after Children	Service Manager, Looked after Children
Salford Children's Services Duty and Assessment	Duty and Assessment Team Manager
Salford Royal NHS Foundation Trust Health Visiting	HV Cluster Lead
Salford Royal NHS Foundation Trust Diana Nursing	Community Nurse.
Salford Royal NHS Foundation Trust Community Paediatrics	Community Paediatrician
Salford Royal NHS Foundation Trust Occupational and Physio Therapy	Physio Therapist
Salford Royal NHS Foundation Trust	Named Nurse
Salford Royal NHS Foundation Trust Health Visiting	Community Nursery Nurse
Salford Royal NHS Foundation Trust Occupational and Physio Therapy	Occupational Therapist
Salford Royal NHS Foundation Trust Occupational and Physio Therapy	Paediatric Occupational Therapist
Salford Royal NHS Foundation Trust Speech and language Therapy	Targeted Services Matron.
Salford Royal NHS Foundation Trust Speech and Language Therapy	Speech & Language Therapist
Salford Royal NHS Foundation Trust Speech and Language Therapy	Speech & Language Therapist
Salford Royal NHS Foundation Trust Speech and Language Therapy	Nurse and AHP Manager Targeted Services
Salford Safeguarding Children Board	Training Officer
Salford Safeguarding Children Board	Senior Business Support Officer
Salford Safeguarding Children Board	Training Coordinator
Salford Safeguarding Children Board	Interim Business Manager
Salix Homes	Neighbourhood Manager