



Cornwall and Isles of Scilly Safeguarding Children Board

Serious Case Review (this document has been redacted to remove information relating to personal details that do not contribute to the recommendations of the report. The Board sanctioned the amendments to the original report in order to deal with sensitivities of the family)

Young Person who died in February 2013

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INDEX

| <u>Title</u> | <u>Page</u> |
|-----------------------------------|--------------------|
| Introduction | 3 |
| Methodology | 3 |
| Sources of data | 5 |
| Case Summary | 6 |
| Themes and recommendations | 7 |
| Conclusion | 20 |
| Appendix 1 | 21 |
| Appendix 2 | 22 |

1. Introduction

1.1 The circumstances of this child's death (referred to within this report as the 'Young Person') was considered by Cornwall and Isles and Scilly Children's Safeguarding Board (the LSCB) and it was agreed that the criteria for a serious case review (SCR) as set out in Chapter 4 of "Working Together to Safeguard Children - a guide to inter-agency working to safeguard and promote the welfare of children" March 2013 were met. "Working Together" is the primary source of guidance with the Children's Acts around the legal framework to protect and safeguard children. The SCR was formally commissioned in June 2013 under this framework.

2. The Child Death Overview Process

2.1 From 1 April 2008, Child Death Review processes became mandatory for Local Safeguarding Boards in England. The process to be followed is outlined within "Working Together." The child death review process for this death has yet to be concluded.

3. Current criminal Investigations, care proceedings and coroner's inquiries

3.1 There are no criminal, or care proceedings in this case. The inquest is yet to be heard.

4. Family Composition

4.1 The young person lived at home in a rural location with her parents. She was the youngest of four siblings. Her older siblings had left home to live as independent adults. The young person kept in touch with her siblings and they continued to be part of the young person's life to varying degrees. There are no living maternal or paternal grandparents and no other relatives were actively involved in the young person's life.

5. Glossary of Terms

The glossary of terms pertaining to this review, are at **Appendix 2**

6. Methodology

6.1 There have been considerable national developments around methodology for child serious case reviews in recent years. This work has been driven by the need to improve the quality of serious case reviews, and to support LSCB's to secure improved outcomes for children and their families. Under "Working Together" LSCB's have an enhanced accountability to engender a learning culture and embed learning across all agencies through a defined learning and improvement framework.

6.2 When the young person's death was first considered by the LSCB, the publication of the revised statutory guidance, "Working Together to Safeguard Children"- was

imminent. By the time the serious case review was formally commissioned the new guidance had recently been published and was in the process of being assimilated by all LSCB's.

6.3 The updated guidance in 2013 was informed by Professor Eileen Munro's report on child protection to the Government in May 2011. This stated LSCB's should use systems methodology when undertaking serious case reviews. Cornwall LSCB was part of a pilot funded by the Department of Education in 2011 using systems methodology for serious case reviews in anticipation of the revised guidance.

6.4 The statutory guidance in 2013 refers to principles to be applied by LSCB's in the context of continuous learning and improvement and that the approach to SCR's should be proportionate according to the scale and level of complexity of the issues being examined. This and other principles were incorporated into the terms of reference for this review. LSCB's under this guidance may use any model of systems methodology which is consistent with the principles within "Working Together".

6.5 For this review the LSCB opted for a "hybrid" methodology building on an approach developed in a previous SCR by an independent author of a previous SCR and the LSCB development manager. This involves the use of risk grids to reflect upon professional practice in the context of the systems in which professionals work. This methodology will be further appraised by the LSCB in due course.

6.6 The methodology is based upon a collaborative collation and analysis of the facts of this case to capture the what, why and how. The methodology used two facilitators (one independent and one internal). The facilitators managed the review working with representatives from each agency involved with young person and her family, who in turn supported many of the frontline professionals who were also involved in the face to face analysis work to capture learning. As the review unfolded it became apparent that there was one particular aspect of the review that would require national expert medical opinion. This meant that it has not been possible to conclude the serious case review in the usual six month window and the appropriate authorities were informed accordingly. The expert opinion has proved to be an invaluable component of the review much of which is replicated in this report.

6.7 In keeping with systems methodology the review establishes findings, lessons and recommendations are made. However, the report does not contain action plans. It is for the LSCB to consider the recommendations and then agree the priorities to improve systems and outcomes. In this way the LSCB are more empowered to meet their accountability and duties as contained in the statutory guidance.

7. Terms of reference

7.1 "Working Together" does not refer to "terms of reference" as such. However, whatever methodology is chosen for a review, a written agreement should be agreed to provide clarity on scope and remit of the review. The Department of

Education have stated that there is no reason why such a statement might not still be called terms of reference.

7.2 The main time span the review has focused upon for analysis is the last three years of young person's life, i.e. from February 2010. That is not to say that information prior to this period is not considered for context but a system review focuses on a limited period of time before the death, or significant incident. If one analyses too far in time, many of the systems will have already changed. Family history and historical professional practice is significant but in the sense of what the professionals know and understand of this when managing the child and her family. The methodology used in this review does not include a lengthy chronology to be attached to this report but there is a case summary which incorporates the timeline.

8. The review panel

8.1 The review panel is made up of senior representatives from the different agencies who were involved with the young person and her family during the period under review. The agencies were:-

- **Child and Adolescent Mental Health Service (CAMHS)**
- **Paediatric services for the Community and Hospital**
- **Primary care for the GP and Out Of Hours service**
- **Children's Social Work and Psychology**
- **Secondary Education**
- **Elective Home Education Service**
- **Police**

There was also a great deal of input from frontline professionals involved with the child other than a psychologist who had left the employ of the mental health trust and declined to be involved despite this being a statutory process. There was however senior representation on the review team from CAMHS.

9. Sources of data.

9.1 The primary source of data comes from the review panel, front line professionals who worked with the young person and family members. There was also consideration of key educational, medical and social care records. Relevant policies and protocols were also considered.

9.2 The review panel completed risk grids for their respective agencies to reflect upon all aspects of professional involvement with the young person on a single and multi-agency basis.

9.3 Further data was ascertained from looking at national guidance and policy in the context of expert advice into the review. This expert opinion came from Dr Paul M Davies, Consultant in General and Community Paediatrics and a national leader and

expert in the field of Fabricated or Induced Illness (formerly referred to as Munchausen Syndrome by Proxy). The opinion was produced for the SCR alone.

10. Case Summary

10.1 The young person was a 16 year old girl with a diagnosis of atypical Asperger's, anxiety, and a longstanding history of constipation. On 8 February 2013, the young person collapsed suddenly at home and died having suffered a cardiac arrest. It is thought this was caused by significant abdominal distension arising from serious and longstanding constipation. The Coroner for Cornwall concluded at the inquest that the cause of death was "natural causes contributed by psycho-social factors".

10.2 In January 2013, the constipation was severe again and the young person took some homeopathic remedies which the young person said made her feel better but her stomach started to be distended and the young person refused to take conventional medicines. Three weeks before her death they spoke to the GP and he agreed to prescribe stronger laxatives but the young person was saying that she had abdominal pain and in particular at night. The GP thought it would be sensible for the young person to go to the hospital but the young person's previous experience of hospital was poor and they felt that she would need considerable support and preparation for any admission to hospital. The young person's parents do not feel health professionals understood the extent of her fear of going to hospital and this was not considered.

10.3 The young person's older sibling saw her a few weeks before she died and noted her to be very low in mood but she had no inclination of what was to come.

10.4 On 7th February 2013 the young person's mother rang the Out of Hours GP Service at 23.29 due to how unwell the young person was and a home visit was agreed. The parents said that the young person may not be compliant with being examined. The young person did speak to the doctor but refused to go to the GP or be admitted to hospital. The young person refused assessment but required treatment and did accept the suggestion that a district nurse visit her at home to give her an enema.

10.5 On 8th February 2013 parents made a further call to the Out of Hours GP Service at 03.00 in the morning as the young person's condition had deteriorated and she had pains in her chest. An emergency ambulance attended the home address. They recall that the ambulance staff wanted to take the young person into hospital when they heard the history. The young person was refusing to be fully examined. The young person's mother recalls explaining to the ambulance staff that if the young person went into hospital then there could not be bright lights, and it would need to be quiet for her. The ambulance staff said they could not guarantee that. The young person refused to go to hospital and her mother felt that was the young person's choice. Her mother felt that they had a physical and spiritual responsibility for the young person and respected the young person's decision. The ambulance left.

10.6 Literally only minutes after the ambulance left the young person said she had a pain in her shoulder and her mother massaged her. The young person then started to vomit green fluid and as she was being helped by her mother into the bathroom the young person collapsed. The ambulance was recalled via 999 and they came back immediately as they were only down the road.

11. Learning themes and recommendations

11.1 From the review analysis a number of themes emerge from which learning points and recommendations have been extrapolated. The LSCB has accepted the recommendations for learning and action detailed below. One of the emerging themes on analysis was the identification and management of possible fabricated and induced illness (FII). For this element expert opinion was sought and this is included in the relevant sections. The review is very grateful for the input and guidance provided by the expert who is a leader in the field of FII.

11.2 The learning themes are:-

- 1. Consider and understand the voice of the child and their lived experience.**
- 2. Inter-agency co-ordination to a chronic health problem.**
- 3. Considerations when a child exits mainstream education.**
- 4. Professional response to parental mental health problems.**
- 5. Identification and management of suspected FII.**
- 6. The child who refuses health care.**

12. Consider and understand the voice of the child and their lived experience.

12.1 The young person was assessed as having adequate features to diagnose a mild and atypical autistic disorder. This was a pragmatic description of how she was functioning at that time and was supported by the learning disability social worker. The psychiatrist was at pains to emphasise that this was atypical and not like classical 'genetic' autism but may be related to the young person's prenatal issues of being premature. Other professionals highlighted features that would be incompatible with autism and questioned the diagnosis and they were also correct. This is not an uncommon situation with children who have specific learning disabilities. If an autism diagnosis is likely to be useful to the child, e.g. if it attracts an appropriate educational resource, and if they meet the defined diagnostic criteria, albeit on a borderline basis, then it is not unreasonable to use the label. It does not preclude other diagnoses and should not stifle the debate about the nature and causes of the child's problems. In other words an autism diagnosis should not define everything about the child, it simply is useful shorthand for describing aspects of the child's functioning that appear to need a specific supportive input.

12.2 Later, the educational psychologist identified that the young person had wide variations in her abilities in different areas of assessment (referred to as a 'spiky' profile when discussing educational needs). Some of her abilities were above average giving the impression of a bright, vibrant girl who could achieve good

educational outcomes. Other abilities were very low and indicated that she was likely to have significant difficulties with some aspects of learning. This kind of patchy specific 'block' in certain aspects of neurological functioning is well recognised in children who have prenatal or perinatal events such as prematurity, intrauterine growth retardation or birth asphyxia but is also seen in some children without these background issues.

12.3 The young person seems to have presented as a very anxious girl and, perhaps more specifically, she was highly avoidant of certain things, a phenomenon known as 'demand avoidance'. The young person does not appear to have the full features of 'Pathological Demand Avoidance' as a specific diagnosis. Demand-avoidant children can be impossible to persuade, very variable and confusing to others because they will sometimes do things, and sometimes not, which can be very frustrating. The extent to which this is an innate problem or learned from other people around the child is always difficult to define.

12.4 However, the danger in this label was not the pragmatic nature in the way it was given and accepted as a diagnosis but the way it defined the young person's life. This diagnosis was always the primary consideration around any decision making for the parents and professionals working with the family. The label also put the young person into a disabled role when there was plenty of evidence from school, CAMHS, social worker and family members that the young person was bright, vibrant and in most aspects a young person who could have been functioning at a higher level with an improved quality of life. The professional challenge on the rationale for this diagnosis and how it impacted upon the young person's life did not come more formally until a new social worker came to be involved with the young person and became a fresh pair of eyes. By then the young person was a teenager. The young person had entrenched behaviours, a fixed and unchallenged family dynamic (despite the attempts from school to push this issue) and despite a great deal of professional activity this did not actually result in any real positive change.

12.5 Professionals were limited by the dynamic and difficulties in working with the family. The young person was not seen or heard in many of the contacts with professionals working with the family. The voice of the child was not heard or accessible. In all the information considered for this review which has been considerable it is not possible to ascertain a clear picture of the young person's views, hopes for the future or what she thought would help her most in life.

12.6 When the young person was seen independently of her family, e.g. at school, and on the rare occasions she was alone with professionals, particularly outside the home, professionals were all struck by how high functioning the young person was but this was in stark contrast as to how she was presented by her parents.

12.7 This stark contrast was observed on a multi-agency basis but no one agency was able to translate this into a defined multi-agency plan which would safeguard the young person even when individuals close to the family passed on their concerns. Ironically, when challenge did then come with a review by the new social worker this

resulted in the young person falling outside the remit of a child in need despite all the concerns expressed at the beginning of the core assessment still existing. Perversely the system worked against the young person in this case.

12.8 The lack of focus on outcomes from the child's perspective historically and during the last three years of her life (which is the main focus of this review) did not deliver improvements for the welfare of the child.

Recommendations – Learning

- 1. Professionals should assess the child and their abilities independently for themselves and outside of any assumptions that may arise from a specific diagnosis. This is a learning point that requires highlighting in the safeguarding processes.**
- 2. Listening to the child is a cornerstone of sound safeguarding. This is vital for a child centred approach. It is notable that despite being an older child Julia was not permitted by her parents to speak to professionals more directly, actively contribute, read or comment upon the second core assessment. It is recommended that professionals are supported by senior staff to challenge any dynamic that blocks the child's viewpoint being clearly expressed.**

Recommendations – Actions

- 3. The time it took to complete the core assessment was inappropriately long. Where input has been requested or when the core assessment is being considered by the family this needs to be within a reasonable deadline. This needs to be made explicit in the assessment process and audited.**
- 4. Core assessments – all agencies need to contribute in a timely fashion and involve families.**

13. INTER-AGENCY COORDINATION AROUND A CHRONIC HEALTH CONDITION

13.1 The young person had physical and psychological health needs and accessed many parts of the NHS health system. For her physical care needs she accessed professionals in primary care (the GP – the main practice and the out of hours service); secondary care - (hospital based paediatricians) and community services (community paediatricians and a specialist continence nurse).

13.2 For her psychological care the young person accessed CAMHS, which is the main component of the health service which provides higher tiers of care where a young person has emotional, wellbeing, and /or mental health difficulties that meet the access criteria. One of the criteria to always be considered is the child's ability to access and engage in, education.

13.3 As a single agency in its own right, health is the most complex in structure and organisation with many components across GP's, community based services, hospital based care and specialist services. The various components generally create and maintain information about individuals separately as a mixture of written notes and some are created electronically. There is no one shared IT information system for the NHS and so it is not always possible for one part of the NHS to easily share information with another part electronically or otherwise. This places a great onus on individual professionals to physically ensure that other professionals in another part of the NHS knows what work they may be doing with the same young person and family. Generally the GP becomes the central point for information for the other parts of the NHS working with a family but then that means that the GP has to coordinate others having access to information about a child and the family to others if anyone is going to really be able to see all parts of the jigsaw and the complete picture. The young person will not always have had the involvement of the same GP whether being seen at her main practice or by the out of hours GP service. Also the young person was seen by many paediatricians in the hospital and the community for generally short isolated episodes and then discharged back to the GP or CAMHS. There was therefore a lack of continuity across primary, secondary care, including out of hours GP care with no clear clinical leader to grip this child's chronic health problem. The care that was delivered particularly was reactive rather than any proactive plan linked to outcomes.

13.4 The young person was constipated from a very young age (certainly, she was referred to paediatrics at 3 years of age and probably the problem would have been quite long-standing before the GP would have referred to secondary care). Constipation and its consequences are mentioned intermittently throughout and there was no period when the young person was clearly stated as being totally free from this problem.

13.5 The young person had not had any serious acute medical crisis relating to constipation prior to the acute illness that led to the young person's death. Over the last few days of the young person's life, there had clearly been an escalation in her symptoms with abdominal pain and reduced feeding. Her parents sought medical advice. The first GP entry that related to this final illness was 22 January, 2 weeks before the young person died, and it is recorded that she had not opened her bowels for 'three months'.

13.6 The GP and ambulance records document that the young person refused to allow a thorough assessment at home or an admission to hospital which was advised. The professionals did not feel able to over-ride the young person's refusal.

13.7 At this stage of her illness, from the symptoms described, it seems unlikely that there was any chance of the young person's problem solving spontaneously. The parents agreed with the young person in refusing effective treatment, and supported the view that the young person should stay at home and have an enema the following day. To be fair to the professionals involved the absence of vomiting,

and the fact that the young person was able to converse and express her views would also have tended to reassure them.

13.8 There are other children with similar constipation-related problems, some of whom have needed emergency surgery (colectomy and ileostomy) and who would have died but for the correct emergency management. Many members of the public and possibly many professionals do not realise that chronic constipation in children can be a fatal condition and a GP is likely to see many cases of constipation but probably would not have seen a potentially fatal case in their career. It would be unreasonable to expect that the young person's parents could have predicted that this illness would prove fatal.

13.9 The clinicians in secondary care had snapshots/windows of opportunity to understand the complexity of the presentation for the young person and her family. However each opportunity was short lived before another doctor took over. The continuity was lost. Each individual acted appropriately bearing in mind how common idiopathic chronic constipation is within paediatrics. However, an opportunity may have been missed due to a lack of continuity. Also when the young person failed to attend appointments this was not effectively followed up.

13.10 In this case therefore there were a significant number of different paediatricians and GP's over time dealing with the same issue of the young person's constipation. Although each decision around medical management seems to have been acceptable at the time of the appointment and seeing the young person, the chronic management issues surrounding the review of a non-engaged child alongside that of a dominant parent, were not fully understood and did not result in substantial changes to the management strategy. This lack of understanding of the family dynamic was detrimental to the young person. During this period of time, changes to service provision also meant the loss of continuity of care and care via the continence nurse advisor. The gravity of the young person's deteriorating condition prior to the death was not recognised within primary care either and not brought back to the attention of secondary care; however it is not clear if this would have made any difference to the final outcome, i.e. the young person's tragic death.

13.11 GPs and paediatricians are unlikely to see a fatal case of chronic constipation in their working career. However, it does occur as to do non-fatal but very serious sequelae requiring surgical intervention. The management of chronic constipation however can be fraught with difficulty when parents/carers/children are not in agreement with management plans such as in this case where the young person was receiving a number of conventional and alternative therapies at different times with no clear and consistent plan. There is guidance to support professionals and families from the **National Institute for Health and Care Excellence (NICE) 2010 and updated; 'Constipation in children and young people: diagnoses and management of idiopathic childhood constipation in primary and secondary care'**.

13.12 As a result of the above inhibitors in the system, there was no well led cohesive or comprehensive plan to manage the young person's chronic problem of constipation by the GP or secondary care.

13.13 In terms of the CAMHS service, the professionals made a determined and focussed attempt to address the issues that were within their domain. The young person had quite a large amount of professional input over a number of years. However, the psychologist was hampered in that the problems presented were not the 'real' problems. In other words, they were attempting to treat the *end results* of a situation rather than the underlying situation itself. The volume of input to the young person was positive but did not really address the family dynamic for instance and to help the young person a whole system family approach was required to address the unmanaged anxieties of other family members.

13.14 The professionals at CAMHS did not show faith in their conviction in the suspicions around FII. While that part of health as an agency had those concerns this was not shared with all health professionals working with the family. The GP was totally unaware for instance and had not thought of as a possibility. It is recorded that the social worker and psychologist were in agreement that the presentation did fit for possible FII. This was not followed through nor was there stronger challenge around parental mental health concerns and one would have expected for the psychologist to be pushing at the door of child protection to escalate matters through those processes. It would seem that CAMHS was reassured that the new social worker had identified a list of concerns that would be addressed through via the core assessment.

Recommendations – Actions

- 1. The integration programme for health and social care should consider the viability of shared IT systems to allow professionals across various health providers in the community and the hospital to better understand the child's needs outside of the one dimensional outpatient clinic appointment. In the interim some form of local memorandum of understanding between the various components of health would assist along the lines that exist for multiagency information sharing. This should include information about the parents on a need to know basis for safeguarding**
- 2. It is recommended that the NICE guidance for this chronic condition is acknowledged and fully adopted across all health immediately.**
- 3. An audit of organisations' DNA policies is recommended to support practitioners to 'think safeguarding' at each opportunity.**
- 4. Primary care needs to conduct a governance review/audit upon repeat prescribing practice in the context of sound medicines management and safeguarding children.**

5. **Multi agency professionals should be reminded that the GP must be involved/informed of any work or care being instigated with the child as they are often the lead clinician in the community and need to have this information at hand when they see the child and other family members. Only then can the GP make fully informed decisions in the best interest of the child and be properly involved in safeguarding effectively.**

14. CONSIDERATIONS WHEN A CHILD EXITS MAINSTREAM EDUCATION

14.1 The young person had an appropriate assessment of her educational difficulties by the Local Education Authority (LEA). A careful plan was set up for the young person however, the plan was sabotaged by poor attendance, non-compliance, and arguments over peripheral issues. An alternative plan was put in place for the young person. This was far less likely to be successful and the goals were much more modest for educational attainment. This too was sabotaged by non-compliance. A third strategy was then arrived at, with the young person being removed from the school roll by her parents and electively home educated.

14.2 Parents may decide to exercise their right to home educate their child. Parents are not required to seek approval from the local authority to educate their children at home. Parents must also ensure that their children receive suitable full-time education for as long as they are being educated at home.

14.3 Parents' right to educate their child at home applies equally where a child has a Statement of Special Needs which the young person had. This right is irrespective of whether the child has a statement of special educational needs or not. Where a child has a statement of SEN and is home educated, it remains the local authority's duty to ensure that the child's needs are met.

14.4 The system around EHE is based around the legal framework and the law relating to elective home education states;-

1.1 The responsibility for a child's education rests with their parents. In England, education is compulsory, but school is not.

1.2 Article 2 of Protocol 1 of the European Convention on Human Rights states that:

"No person shall be denied the right to education. In the exercise of any functions which it assumes in relation to education and to teaching, the State shall respect the right of parents to ensure such education and teaching is in conformity with their own religious and philosophical convictions."

Parents have a right to educate their children at home. Section 7 of the Education Act 1996 provides that:

"The parent of every child of compulsory school age shall cause him to receive sufficient full-time education suitable-

(a) to his age, ability and aptitude, and

(b) to any special educational needs he may have,

either by regular attendance at school or otherwise."

1.3 The responsibility for a child's education rests with his or her parents. An "efficient" and "suitable" education is not defined in the Education Act 1996 but "efficient" has been broadly described in case law as an education that "achieves which it sets out to achieve", and a "suitable" education is one that primarily equips a child for life within the community of which he is a member, rather than the way of life in the country as a whole, as long as it does not foreclose the child's options in later years to adopt some other form of life if he wishes to do so".

2.7 Local authorities have no statutory duties in relation to monitoring the quality of home education on a routine basis.

14.5 Home educating parents are not required to:

- Teach the National Curriculum
- Provide a broad and balanced education
- Have a timetable
- Have premises equipped to any particular standard
- Set hours during which education will take place
- Have any specific qualifications
- Make detailed plans in advance
- Observe school hours, days or terms
- Give formal lessons
- Mark work done by their child
- Formally assess progress or set development objectives
- Reproduce school type peer group socialisation
- Match school-based, age-specific standards.

14.6 However, local authorities should offer advice and support to parents on these matters if requested.

14.7 Where Elective Home Education should be raised as a safeguarding issue is when there are pre-existing safeguarding concerns and EHE may have become a default pathway after professional relationships have broken down. In that situation, it is arguable whether the home education is truly 'elective' or whether it simply is a form of 'closure' in the safeguarding sense i.e. is a family choosing to avoid or disengage with certain professionals from whom they feel scrutinised.

Recommendations – Actions

- 1. That the Children's Trust Board reports to the LSCB on an annual basis with regard to the satisfactory provision and actions taken in relation to home educated children. (Reference: Report to the Secretary of State on the Review of Elective Home Education in England. Graham Badman).**
- 2. The Department of Education considers the learning arising from this serious case review in relation to safeguarding concerns where children and young people are subject to 'Home Elective Education'.**

15. IDENTIFICATION AND MANAGEMENT OF SUSPECTED FABRICATED OR INDUCED ILLNESS (FII)

15.1 In this case FII was suspected but not proven and the review identified that professionals did not know how to take that forward or with whom. There were no professional differences as such but no one agency was able to respond and grip the FII suspicions and therefore there could be no multi-agency response. Despite these concerns the case was closed to social care after the second core assessment in 2012 and CAMHS finished their work with the young person in the summer of 2012. The young person stopped attending school for a considerable period of time. One reason for this is that the complexities of the young person herself and the family dynamic were difficult to manage and this review concluded that the infrastructure, process and professional knowledge to appreciate the spectrum of such cases was not present.

15.2 In the 2009 Royal College of Paediatricians and Child Health guidance on FII for paediatricians, it was attempted to clarify the definition of fabricated or induced illness (FII). 'True' FII, from the point of view of paediatricians, should be reserved for cases where the evidence points to the child's carer deliberately lying about illness or deliberately causing illness in the child and presenting the child for medical attention, often repeatedly, in an attempt to 'dupe' the doctors and procure medical investigation and treatment. Often in the process, the parent assumes a 'sick role' by proxy, gaining status as a carer for a child with a serious illness which, perversely, they have caused.

15.3 That is unlikely to be the dynamic here as the number of presentations of the young person to doctors for physical health ailments was fairly modest considering the problems she had, and the only persistent physical complaint, constipation, was genuine.

15.4 Many cases of this nature drift for years or are never addressed, and the child moves into adult life with variable or unknown outcomes. Some children survive and become functional adults others persist with abnormal illness behaviour into adult life. There is some published evidence on outcomes of children exposed to FII behaviour but case definitions are variable and the exact risks are not clear. There is a however a spectrum to be appreciated and this case fits more into a "scenario 2" formulation where features detailed below are present to varying degrees but are detrimental to the child. Such features make these cases difficult and may include:

- Persistent denial by the carer and an inability to reconcile the carers' views with those of the professionals.
- The carer will use their medical knowledge in a way that tends to paralyse the professional response.
- Carers obstructing contact with the child. There is no way that professionals can gain sustained or good quality time with the child unless there is a formal safeguarding process.

- It is often the case that one or more professionals assume the role of advocate for the carer and lose sight of the impact of the carer's behaviour on the child.
- Inappropriate reassurance is taken from small, insignificant or unsustainable gains, even though the child's prognosis has not altered materially.
- Changes of personnel make continuity and an effective overview of the case difficult. The carer's tendency to 'sack' staff as soon as they attempt to address the real underlying issues makes this even more likely. These cases are often given to new or inexperienced staff when they need really strong case management.
- The child will generally not ask to be protected and will be hostile to the safeguarding intervention. Older children usually support their carer, who is of course their primary parenting axis and the most secure position in their lives, even if the relationship is very disordered. The child may feel responsible for their carer who may have inappropriately relied on the child to try to meet the carer's emotional needs.
- Older children will experience secondary psychological gain from the experience of being presented as a disabled child and may learn to persist in this pattern of behaviour even in the absence of the carer.
- The child may present well in interview and professionals may take false reassurance from the child's relatively normal interaction or appearance.
- Carers will rarely present themselves for a formal mental health assessment and even if they do, the mental health professional may not have a clear understanding of the issues affecting the child and the carers usually present with few if any features of formal mental illness. Detailed personality assessment requires knowledge of past behaviour (which is often not available or is denied), and expertise which only the more senior members of the adult mental health team may possess. Interventions are usually focused on helping the carer rather than informing the safeguarding process.
- It is difficult to present evidence in a way that would satisfy a legal test, even in a civil court, and therefore legal advice (if it is sought) is often against initiating legal proceedings.
- Even if there is evidence at a civil level of proof, it is often very difficult for Children's Services to know what the plan for the child should be. The child often appears to have a very strong emotional dependency on the parent and it would seem extreme and risky to separate child and parent, but anything short of this is likely to fail, as persistent contact with the carer is very difficult for the child to handle emotionally.
- The negative publicity around 'Munchausen Syndrome by Proxy' in the late 1990's and early 2000's has left a legacy of mistrust and insecurity in professionals that still pervades these cases.

Recommendations – Learning

- 1. LSCB to commission training for specific professionals around the identification and management of suspected Fabricated Induced Illness cases and capture 'best practice' and the learning identified within this serious case review.**
- 2. LSCB to agree an overarching practice protocol around Fabricated Induced Illness to bring clarity on management for the spectrum of cases. This is currently being considered using shared approaches and polices used nationally in preparation to adopt best practice for FII. This will need to be actively promoted by the LSCB and then adopted multi agency. This needs to remind professionals around information sharing protocols and their importance.**
- 3. Family members outside the parents appear to have had quite a good insight into the underlying problems that were impacting on the Young Person's life and brought this to the attention of Children's Services. Good practice should be followed in that:-**
 - Family members reporting their concerns need to be listened to, have their concerns acknowledged, recorded and followed up. These concerns should be included in chronologies.**
 - Family members who contact agencies do so based on their observations of the child, parents' behaviours and/or their previous experience of being parented by the parents and this should be acknowledged.**
 - Where it is a sibling reporting this may be because they do not want what happened to them to be repeated in their younger sibling.**
 - They may have concerns in relation to the mental health of their parents.**
- 4. All family contact should be recorded and needs to be taken seriously, respected and given credence in relation to the information provided when assessing children especially where Fabricated or Induced Illness (FII) is hypothesised. It is recommended that:-**
 - The child's and family's confidentiality needs to be respected at the same time as information is gathered and the child's welfare is promoted. This should not be a barrier to safeguarding the child.**
 - This should include family members and other non-professionals who want to share information as part of the assessment process.**
 - When such contact is outside of the assessment process this information needs to be considered in light of a chronology of significant events.**

- All cases need a detailed chronology when FII is being considered to ensure robust analysis of risk and identification of patterns of behaviour.

Recommendations - Actions

5. A multi-agency consultation group to consider cases where FII is considered should be established.
6. Social care, when contacted, needs to evaluate the information gathered and share with relevant agencies, and ensure that the views of medical professionals are part of the decision-making process, especially when FII is suspected. That said, it will be necessary to challenge where there is a difference of professional opinion and where necessary to escalate using the LSCB escalation policy.
7. Where possible a multi-agency (integrated) chronology should be used to establish patterns of behaviour, share information and identify risk.

16. PROFESSIONAL RESPONSE TO PARENTAL MENTAL HEALTH

16.1 The expert view and one that this review accepts is that it is likely that the young person's mother was presenting the young person's problems as a *proxy* for her own emotional distress. What this effectively means is that the professionals were trying to 'treat' the mother's emotional, mental health or personality difficulties *through the medium of the young person*. This was always going to fail, as this is not an effective way to address the mother's needs. Those needs could not be met by the professionals attempting to help the Young Person.

Recommendations – Learning

1. There should be effective challenge of parental attitude toward their, own mental health needs to ensure it is seen as essential in attaining positive parenting. The potential impact on the child should be clearly set out- as long as this would not put the child at greater risk
2. Indicators of risk should be understood by all agency members, not to be used without discretion, but to be considered in reflective supervision in all cases as a checklist of risk factors.

Recommendations – Actions

3. The impact of parental mental health on their ability to parent needs to be explored under parenting capacity and whole system family therapy and other therapeutic approaches used if indicated.

4. **If a parent alludes to previous mental health needs but does not directly give permission for this to be explored with their own GP, then advice needs to be sought from mental health professionals/legal team.**
5. **Where parents do not consent to take help and their mental health influences positive parenting consideration should be given to escalation to multi-agency discussion – Early Help & Multi-Agency Referral Unit.**
6. **GP's have a major role to play in supporting the parent with mental health problems in the family context and in taking forward the safeguarding concerns if they arise. It is recommended that GP's safeguarding leads emphasise this in the mandatory child protection training programmes and GP accountability and responsibility to be proactive rather than passive.**

17. A CHILD WHO REFUSES HEALTH SERVICES/CARE

17.1 There is the general issue of young people withholding consent for necessary medical procedures. The young person would have been regarded as being of sufficient age and understanding to consent though her Asperger's diagnosis and known difficulties would have been taken into account. If a young person of her age refused life-saving treatment then usually that refusal would be over-ruled. Doctors can act to save life in an emergency if it is physically possible to do so. That option was not available here; it was very difficult for the GP and ambulance crew to physically remove the young person to hospital against her will, certainly not without the active support of the parents and they supported the young person's refusal to go to the hospital. The young person would have had to be restrained if she could not be persuaded to go, and it is not reasonable to expect health staff to do that. If they had believed that the young person's life was at risk and the timescale allowed, then the Health Trust would have had to apply to a court with or without the assistance of the Local Authority. In this case this would have required urgent legal action. This would have been difficult on the night of 7/8 February but it would have been an easier option on 5 February. If health professionals were gravely concerned they should have sought urgent legal advice though it is unclear from this review whether some health professionals understood this process.

17.2 There is nothing to suggest that the GP or parents perceived that level of urgency at the time. Nor was there any consideration for a capacity assessment to establish if the young person's illness was impairing her cognitive ability to understand the consequences of refusing care.

17.3 The GP and ambulance staff all clearly considered it was in the young person's best interest to attend the hospital and be assessed there more fully but she declined and her parents accepted this refusal as the young person exercising her rights of autonomy and self-determination. The young person's parents could not have foreseen the consequence of this though it was apparent that the young person was very ill.

Recommendations – Actions

- 1. Health staff need to be reminded of the legal framework around consent for children who would be deemed to be competent to consent but are refusing treatment or care that health professionals deem is necessary and is in the best interest of the child. This should include going to hospital even when the primary objective of being seen at the hospital is to assess rather than treat immediately. Professionals should understand that on occasions proportionate force is required and proportionality is considered in terms of the gravity of seriousness. The more grave the situation the more proportionate it is to use reasonable force**
- 2. Professionals need to undertake formal assessments of mental capacity within the legal frameworks so that they can assess if a child can understand the consequences of not being treated and whether they can weigh that up and make a truly informed choice. All assessments of this nature must be recorded in detail and conducted with the child alone preferably to prevent any overt or covert duress or coercion from family members either way. This relates to the Fraser guidelines and whether a child would be considered primarily to be competent to consent to care.**

18. Summary of Good Practice

18.1 It may seem strange speaking of good practice when a child has died but good practice should also be captured and good practice points are highlighted in relevant parts of this report.

18.2 There is evidence of best practice at the last school the young person attended to meet her needs and they did all they possibly could to keep the young person engaged in education and attending mainstream school. They also committed to the many discussions around the young person and sought to work effectively with other professionals to enable and empower the young person to reach her potential.

18.3 CAMHS were able to provide the same practitioner to work with the young person and provided a great deal of input which the expert considered impressive.

19. Conclusion

This review has highlighted many learning points and in areas that present real challenge to professionals around decision making where there may be an indication of FII, or where a chronic medical condition requires a sophisticated approach due to complexity. For children who need additional help every day matters and the child's needs must always be paramount. It is hoped that the LSCB embrace the recommendations from this report and on considering the recommendations be better able to safeguard children as a consequence.

APPENDIX 1

Terms of reference

General terms

This serious case review will be conducted in such a way as to:-

1. recognise the complex circumstances in which professionals work together to safeguard children
2. understand precisely who did what and the underlying reasons that led individuals and organisations to act as they did
3. understand practice from the viewpoint of the individuals and organisations involved at the time rather than using hindsight
4. be conducted fairly, with impartiality, thoroughness, and with accountability and transparency.

Specific terms

1. Was the response by health services to the child's medical condition timely and appropriate.
2. Was everything that could have been done, to examine the causes of the condition.
3. Were the suspicions expressed by the school of inappropriate responses by the parents around the child's health problems taken into account and assessed.
4. Was information shared appropriately and effectively between agencies particularly in relation to concerns expressed by some professionals around possible fabricated illness.
5. Was information shared effectively around concerns expressed by a family member around the child's care.
6. Were there any professional differences about the causes of the child's health problems and if so were these appropriately addressed and resolved in line with the Resolving Professional Differences Policy

APPENDIX 2

Glossary- terms, acronyms and abbreviations used

Agency - organisations that are working around the child and family with different public functions e.g. social care, health, education.

ASD - Autistic spectrum disorders

Asperger's – a form of autism

CAMHS - Child and Adolescent Mental Health Services

CBT- cognitive behavioural therapy

CCG - Clinical Commissioning Group

CIN - child in need – a child who is unlikely to achieve or maintain a satisfactory level of health or development, or their health and development will be significantly impaired, without the provision of services; or a child who is disabled. A child is assessed and this is called a core assessment.

CHES - Community Hospital Education Service

Dyscalculia - difficulty in acquiring arithmetical skills

EHE - Elective home education

Fraser guidelines - set of questions that test if a child is competent and mature enough to make decisions about their care

FII - fabricated Induced illness

GP - General Practitioner

LSCB - Local Safeguarding Children's Board

ME - myalgic encephalopathy/chronic fatigue syndrome

NICE - National Institute for Clinical Excellence

OOH – Out of hours (medical service provided out of core hours when the GP practice is not open)

Primary care - care provided in the community by GP and associated professions

Secondary care - provision of care on from primary care, eg, hospital care

SCR - Serious Case Review

Safeguarding - the actions we take to promote the welfare of children and protect them from harm

SW - social worker