EXECUTIVE SUMMARY

SERIOUS CASE REVIEW

01/08

Commissioned by the

Vale of Glamorgan Safeguarding Children Board

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INTRODUCTION

1. In January 2005, concerns about possible ineffective inter-agency working with Child Z and her family led to the NHS Trust asking the ACPC (as it then was) to consider a Serious Case Review. The Serious Case Review Panel met and recommended a Review be undertaken.

2. An external author for the Overview was commissioned because of the complexity of the case and the involvement of a health specialist tertiary hospital.

3. The Vale of Glamorgan Council made both parents aware of the Review. The Chair of the Serious Case Review Panel wrote to Child Z's mother via her solicitor; however, she did not wish for any involvement. The Chair also wrote to Child Z's father; he did not reply.

4. The DebRA Charity (a charity working on behalf of people in the UK with the genetic skin blistering condition Epidermolysis Bullosa (EB) were also asked to contribute as Child Z's mother had had some contact with them. They support nursing staff who are based at Hospital 3 and were therefore included in their Review.

5. The Serious Case Review Panel had membership from the key agencies and was chaired by the National Society for the Prevention of Cruelty to Children (NSPCC).

6. The contributors to the Review were:

   - Vale of Glamorgan Children's Services (Social Services)
   - South Wales Police
   - National Public Health Service for Wales
   - Hospital 3: a specialist tertiary hospital in England

TERMS OF REFERENCE

7. The Terms of Reference for the Reviews, and the Overview, were to:

   - establish whether there are lessons to be learned from the case about the way in which local professionals and agencies work together to safeguard children;
   - identify clearly what those lessons are, how they will be acted upon, and what is expected to change as a result; and as a consequence,
   - improve inter-agency working and better safeguard children, *and*
   - identify examples of good practice.

CONTEXT

8. There are two key contextual considerations in reading this report; EB and Fabricated/Induced Illness. Both are rare and it is important to acknowledge that few health professionals will have seen a case of either in their career.

EPIDERMOLYSIS BULLOSA (EB)

9. Epidermolysis Bullosa (EB) is a rare genetic condition in which the skin and the internal body linings blister at the slightest knock or rub. This can lead to painful open wounds. EB can present in a number of ways and there is a wide variation in severity because of the number of different gene mutations. A feature of sufferers is parents who may be related. One form of EB presents by shedding of the nails. A US report cites an incidence of 2 to 4 per 100,000,[1] whereas the UK incidence is said to be 1 per 17000[2]); thus most health professionals would not see a case during their career. The type of EB from which Child Z was thought to suffer was the autosomal recessive genetic variety which is even rarer (only 25% of known cases are of this type) and therefore the prevalence within the population is lower than the 1 in 17000 live births (there are likely to be only 1250 cases in the population). Further information about EB can be found in Appendix 3.

FABRICATED OR INDUCED ILLNESS (FII)

10. Similarly, fabricated or induced illness is also rare: at 0.5 per 100,000 children and 2.8 per 100,000 for children under one[3].

11. FII involves fabrication of signs and symptoms by a carer: often resulting in extensive and unnecessary medical investigations in order to establish the underlying cause. The child may have treatment or operations which are not necessary, and spend time in hospital.

12. The identification of FII falls primarily to paediatricians, who come to consider it as a possibility when the child's presentation does not accord with any known condition from which the child suffers and when reported features about the child are not explained by clinical examination and investigations and may not be observed independently of the reporter. As such, it is a medical diagnosis.

13. It can thus take some time for a diagnosis; Hospital 3, a specialist tertiary hospital, for example, reports an average of 11 months to identify FII.

SUMMARY OF CASE

14. Child Z was born on 14th October 2003. Her mother (aged 32) experienced post natal depression. The relationship between parents was such that father (aged 41) was not always living at home. On 23rd February 2004 a Clinic Assistant noticed that Child Z's nails were red, some were missing and the skin around her fingernails was swollen

[1] NIAMS June 2003
[2] www.patient.co.uk article on EB; Debra Association cited on website: www.debra.org.uk/research/research
[3] Safeguarding children in whom illness is fabricated DfES/DoH/Welsh Assembly Government, August 2002 page 12.

and red. A Paediatrician saw the baby the following day and recorded that “NAI needs to be excluded”. He also referred Child Z to a Dermatologist who diagnosed Child Z as suffering from EB and referred Child Z to a specialist tertiary hospital with expertise in treating children with EB.

15. Over the next eleven months, Child Z experienced a number of hospital admissions with diagnostic processes, sometimes invasive, and treatment. These were interspersed with discharge home and frequent visits, sometimes daily, by the Community Children's Nursing team. In hindsight, the pattern of discharge home, deterioration and readmission was repeated on each occasion. Referrals were made to Social Services who allocated workers, focusing primarily on the need to support Mother in her care of a child with disabilities. The early diagnosis set the context for the way in which all the professionals worked with the family.

16. Between 21st January 2004 and 4th January 2005 Child Z was in hospital on eight occasions.

18. It was, in fact, Mother who was deliberately harming her daughter, and this was finally recognised in January 2005. On 7th March 2005, Mother was charged with GBH, neglect and cruelty. At the subsequent Court Hearing she was found guilty of causing grievous bodily harm and committing an act of cruelty to a child. She was sentenced to 3 years imprisonment on the first count and two years on the second, to run concurrently.

ISSUES IDENTIFIED BY THE REVIEW

22. The advantage of undertaking an overview is that it allows the benefit of hindsight, which of course was not available to those working with the family at the time. The circumstances of this case are probably more complex than most of the situations with which the staff involved with Child Z are involved. It is important, therefore, to acknowledge that both the NPHS and Hospital 3 Reviews identified examples of good practice.

23. The issues identified by the Review were grouped into seven themes.

THEME 1 MOTHER’S MENTAL HEALTH

19. Very little was known about the family. The combined chronology referred mainly to Mother and Child Z; there were some references to Father and a few to maternal Grandmother. There was nothing in the management reviews to suggest that any agency had a picture of this family, or whether they knew of any support for them from their own extended family.

20. The Health Review included early information about Mother’s involvement with the Child and Adolescent Mental Health Services and

to a miscarriage in 2002. This information did not appear to have been known to other agencies.

22 Mother's score on the Edinburgh Post Natal Depression Scale (EPNDS) indicated that she was likely to be suffering from a depressive illness. A referral was made to the Community Psychiatric Nursing Service who allocated a worker; however, the Health Review painted a picture of a professional working in isolation from other professionals and with little awareness of the importance of information sharing.

23. The number of times that Mother contacted professionals should have prompted a question about her own ability to manage; even if Child Z had had EB, it would still have been appropriate to ask that question. Whilst services to support Mother were provided e.g. a funded Nursery place, these were linked to the view that Child Z had a health problem rather than to Mother's own health.

24. The picture conveyed in the chronology showed increasing contact between Mother and professional staff without any discussion of why that might be. There were also examples of Mother "playing off" staff. However, there was neither any real questioning of possible explanations nor was there any link made to mother's mental health.

25. Of additional significance, albeit missed, was the fact that Mother did not appear to follow the advice of health staff or take up offers of help. At the same time as this, the concerns of health staff were escalating but the two were not put together.

THEME 2 EB (Epidermolysis Bullosa)

26. A key factor in this case is the way in which the early diagnosis of EB set the context within which professional interventions were set. The diagnosis appeared to take over and precluded consideration of anything else.

27. The Paediatric Register who first saw Child Z recorded that the presentation was "very bizarre" and that "NAI needs to be excluded". He appropriately sought a second opinion from a Consultant Dermatologist: advising him of the possibility of NAI. He in turn referred Child Z to a Specialist (Hospital 3) for a second opinion but in doing so did not refer to the concern of the Paediatrician in respect of the possibility of NAI.

28. Child Z was thus presented to Hospital 3 as having EB. Hospital 3 also took the view that EB was the likely cause and as this is a specialist tertiary hospital, perceived by local staff to be a centre of excellence, this made it more difficult for staff with concerns about Mother's care to raise these. Hospital 3's Review stated that they were not directly made aware of the child protection concerns until the Child Protection Conference in December.

29. Once he had referred to the Dermatologist, the Paediatrician did not continue to explore whether NAI could be a factor with the same degree of rigour as the follow through of EB as a possible diagnosis. Similarly, the Paediatrician did not take into account mother's behaviour, which was inappropriate whatever the diagnosis.

30. The first referral to Social Services in May 2004 referred to EB and the need for advice and support to Mother. The case was therefore passed to the Children with Disabilities Team. The reference to the diagnosis set the scene for Social Services involvement and this appeared to have influenced, not necessarily intentionally, their responses to information about the child and her mother. The Health Review considered that health staff were unsupported by Social Services.

31. Although the early diagnosis of EB set the context for case management, a diagnosis of EB was never formally confirmed.

32. Local clinical case management did not include a differential diagnosis and whilst Hospital 3 did have one, it was only put in place when the question of FII was formulated by the Social Worker in late December 2004, following her conversations with the local Social Worker.

33. In addition, there was no consideration that even if Child Z had EB, she could *also* be subject to NAI even though there were several examples of behaviour by mother indicating this.

34. The low incidence of EB can lead to a greater reliance on those who do have experience (such as Consultants). This may explain why nursing staff did not question what they were told by mother or what they saw. Without experience of other children with EB the Nurses had no comparators and so accepted what they saw as part of the EB process. Such a gap allows a parent to become the "expert".

THEME 3 PARENTAL CARE OF CHILD Z

35. At birth Child Z was "grossly small" and barely on the second centile when she was admitted to hospital on 21st January 2004 with diarrhoea and vomiting.

36. A child who suffers from EB could fail to thrive because blistering of the mouth and/or throat can cause feeding difficulties whilst blisters in the stomach and intestines can inhibit food absorption. However, the early diagnosis of EB seemed to result in a failure to consider all the possible explanations for Child Z's weight again/loss not following the expected pattern. Child Z was seen to have blisters (ulcers) only twice and so feeding should not have been a problem for her.

37. The Health Visitor and the Community Children's Nurses observed that Child Z was reluctant to feed for her mother but fed well with them. When in hospital, she ate well for nursing staff and often indicated that she was hungry. Staff (Hospital and community) noted that Mother appeared slow or reluctant to feed her daughter, provided

inappropriate food or said she had fed her when this hadn't been observed.

38. Even if EB was the diagnosis, many aspects of Mother's care were unacceptable and should have raised concerns. Considered objectively, these should have painted a picture of a mother who was either chaotic and/or uncaring. Only the local health agency review indicated that this aspect was considered. However, this information did not attract sufficient weighting with the Local Authority to influence the management of the case.

THEME 4 CHILD PROTECTION

39. Although the question of "NAI" as an explanation was raised in February 2004, this was not properly pursued. On several occasions concerns were either not mentioned when they should have been or where they were they were not pursued with any sense of urgency. There were also examples where staff should have asked more questions to establish whether child protection was a factor.

40. Worryingly, given the age of Child Z throughout the period covered by the Review, there was no proper response to four observations of bruising. In such a young (and non ambulant) child this bruising should have raised concern and a referral for investigation under Section 47 of the Children Act (1989).

41. There was a similar lack of attention to other child protection concerns: for example three occasions during one hospital admission on which nursing staff identified and recorded inappropriate actions by Mother to her daughter, resulting in the child's fingers bleeding.

42. Although health professionals raised concerns as early as February 2004, and then on a number of subsequent occasions, there was reluctance by Social Services to activate the child protection procedures.

43. FII as the diagnosis was not made until January 2005; eleven months after Child Z first saw the Paediatrician. There were however, several earlier occasions on which the question about the possibility of FII was either raised, or should have been raised, and followed through.

44. There was no reference to local staff, health or Social Services, referring to the Protocol "Safeguarding Children in Whom Illness Is Fabricated or Induced 2004[4]" or to the FII procedures.

THEME 5 WORKING TOGETHER

[4] produced by the All Wales Child Protection Procedure Group in March 2004 drawn from the Department of Health/Welsh Assembly guidance (August 2002) and the report of the working party of the Royal College of Paediatric and Child Health (Fabricated or induced illness by Carers, February 2002)

45. There were several examples in which internal and inter-agency procedures were not followed. There were also several illustrations of a lack of clarity between agencies; leading to confused expectations and misunderstandings.

46. Staff in the different agencies, or within health services, did talk with each other but whether they always listened or heard each other was less clear. This may have been because they were all influenced by the early diagnosis, or it may be that this would have happened anyway. There were also several occasions when key information wasn't shared.

47. The number of different professionals across so many bases who were involved with Child Z and her mother significantly diluted the ability of any one professional, or even group of professionals, putting together information. This would in turn have impacted on informed decision-making. There was difficulty in sharing information between the different professionals, not helped by the fact that there were several sets of records (even within the same agency).

48. If the information known to the different staff involved had been considered together concerns about the diagnosis and about Mother's care would probably have been identified at an earlier point. Likewise, had any of the professionals involved been able to step back and consider all the information they and others had, or the Initial and Core Assessments been undertaken, they would have been able to see that information which on its own may not have seemed significant became significant when taken with other information.

THEME 6 BASIC PRACTICE

49. There were many examples in the chronology that showed Mother volunteering her perspective to the professionals. This may have had the effect of disarming them so that key questions were not asked.

50. There were also examples in the chronology of a focus on Mother rather than on the child. In addition, Mother deflected staff who appeared to be less sympathetic to her.

51. There were a number of occasions on which the observations of Child Z by the professionals were at odds with her mother's description. There was also a pattern in the combined chronology of Mother not accepting clinical judgements e.g. to discharge Child Z home, and of then drawing attention to herself. On some occasions her behaviour resulted in a change to the plan for Child Z.

52. A key skill in working in child protection is the ability to "think the unthinkable". This requires the ability to consider objectively the available information and to be prepared to look at *all* explanations. Some are obviously more palatable than others. This was missing in this case. It is obviously difficult for professionals to consider that a parent would be harming her own child. In this case, professionals

assumed that Mother's behaviour and thought processes were those of a reasonable person. They didn't ask the question "what if they weren't?"

53. Failure to thrive is a feature of EB and this may have influenced health staff considering that the child's failure to thrive may have been because she wasn't being fed properly. It also meant that this was not considered alongside other concerns about Mother's care.

54. Lord Laming referred in his Inquiry Report to the concept of "respectful uncertainty[5]" It is important to remember that a senior clinician had made a diagnosis in February. This may have made it difficult for nurses to challenge this; i.e. junior staff challenging a consultant. Similarly, from the Nursing perspective, a specialist tertiary hospital appeared to be confirming the diagnosis and so this would have made it even more difficult for them to challenge this

55. The Review noted that access to, and/or the quality of staff supervision varied across the agencies.

THEME 7 ACCESS TO PARENTAL HEALTH RECORDS

56. A key gap in the material available to the Serious Case Review Panel was the parents own health records. There was inference in Child Z's records that both her parents had psychiatric difficulties.

57. The Designated Doctor for Child Protection made considerable effort to gain access to the records, recognising that these could be a critical part of the Review. However, without the agreement of the parents, it was not possible to see these.

MISSED OPPORTUNITIES

58. The analysis of the material available to the Case Review found several missed opportunities to intervene differently with Child Z and had these been taken, she may not have experienced injuries for as long as she did. Some are relatively minor and relate to specific actions which had they been done differently may have influenced the outcome. Others have a greater significance. However, these all have to be placed in a context in which basic procedures[6] were not followed. Had they been there would have been an opportunity to pull together all the information that was known about Child Z and her family and to identify whether she was at risk of injury.

CONCLUSIONS

[5] Laming Inquiry Paragraph 6.602

[6] i.e. undertaking an initial and core assessment, undertaking a Section 47 child protection investigation and following the FII procedures once concerns had been raised that this could be a possibility

59. It was clear from the management reviews that the diagnosis of EB, or the view that this was the diagnosis, influenced the management of this case and given the uncertainty about the form of EB that the child had, resulted in workers accepting symptoms, or mother's reports of symptoms, as part of the disease process. Because EB is uncommon, local staff did not have a knowledge/experience base on which to draw and clearly saw Hospital 3 as a "centre of excellence." This influenced the way in which information from Hospital 3 was received locally.

60. This Review illustrates that the situation with Child Z was very complex. However, the Serious Case Review Panel concluded that at least some of the injuries this child received should have been prevented had staff both shared all the information and followed all the relevant procedures. Similarly, some of the treatment and diagnostic tests, some of which were invasive and undertaken under general anaesthetic, could also have been avoided. The chronology shows that at times Child Z was observed to be "shaking, crying and moaning in pain" and that, on occasions, her tissue was so damaged that the bones on her fingertips were exposed.

61. It was not possible to identify the point at which Mother began harming her child; indeed, there may not have been single start point. Neither was it possible to know whether access to her medical notes or her Community Psychiatric Nurse would have assisted with the answers to the following questions;

- Was there anything in mother's medical history that should have alerted professionals when she became pregnant that her child could possibly be at risk?
- Did the child's first admission to hospital in January offer Mother an opportunity to be the focus of attention which she then needed to continue to receive and find a way of so doing or was the diarrhoea and vomiting a result of Mother's inappropriate care/administration of medication bought over the counter?
- Did the attention Mother received when pregnant meet a need, which was then lost once attention focused onto the baby?
- Did the attention Mother received following her report at Clinic that Child Z's nails had fallen off meet a need? The first appointment with the Dermatologist resulted in diagnosis of EB; which could have reinforced Mother's behaviour and conveyed a message to her that she had deceived them. This was further reinforced by a referral to Hospital 3

62. In addition, the professional perception of a child with disabilities enabled access to financial support e.g. Disability Living Allowance; so it is possible that this could have further reinforced Mother's behaviour (in that if Child Z's condition improved Mother would cease eligibility for the additional income).

63. Absence of access to mother's (and father's) medical notes means that if there is relevant information the opportunity of learning from this is missed which is significant given the low incidence of FII. In particular,

it would have been helpful to identify possible indicators to which Midwives/Health Visitors/Community Psychiatric Nurses could be alert.

64. However, alongside the issues identified in respect of Mother this Review identified, as Laming[7] put it, a failure to do basic things properly. This was especially so in two key aspects; failure of clinicians to have a differential diagnosis and failure of Social Services to undertake neither an assessment (Initial and Core) nor a Section 47 investigation. It was the combination of all of this that resulted in Child Z suffering for much longer than was necessary.

RECOMMENDATIONS

65. Each Agency who undertook a Review, with the exception of the Police whose involvement began only after January 2005, made recommendations to address their learning points. The delay in undertaking this Review means that agencies have already addressed many of these. The Serious Case Review Panel considered, however, that there were additional recommendations to make if all the learning points are to be addressed.

OVERVIEW RECOMMENDATION 1

A Paediatrician who refers a child to a specialist resource should keep an overview of the treatment until such time as the child is discharged from that service.

OVERVIEW RECOMMENDATION 2

All staff should have supervision in accordance with the policy of their agency.

OVERVIEW RECOMMENDATION 3

Where groups of staff from the same discipline or agency are working with a child/family, they should have a group discussion/s with a manager to enable them to share their experiences, pool their information and observations and ensure that they are complying with all relevant policies and procedures. The process for convening and monitoring such discussions needs to be determined by each member agency.

OVERVIEW RECOMMENDATION 4

The draft "ACPC Protocol regarding the Resolution of Professional Disagreements" developed in 2003 be reviewed and revised to ensure that it is line with the current requirements of "Working Together" and submitted to the Local Safeguarding Children's Board for agreement.

OVERVIEW RECOMMENDATION 5

The Local Authority should include in the protocol to be developed between the Children with Disabilities Team and the First Contact

[7] Laming ibid paragraph 6.557

Team the need for clarity about which worker will be responsible for undertaking an assessment or Section 47 investigation.

OVERVIEW RECOMMENDATION 6
The Local Authority should agree a process to ensure that where the Children's Services Directorate becomes aware that a child about whom there are child protection concerns, whether or not they have been formalised, has been referred to a Hospital, the Authority should make contact with the Social Work Department/Service for that Hospital to share relevant information. The process should clearly state who has responsibility for undertaking this.

OVERVIEW RECOMMENDATION 7
Where a Children's Services Directorate convening a Child Protection Conference invites staff from an external Trust, a copy of the invitation should be sent to the Named Nurse/Doctor of that Trust.

OVERVIEW RECOMMENDATION 8
All agencies working with a child must be invited to contribute to any Strategy Discussion which may be held under the child protection procedures.

OVERVIEW RECOMMENDATION 9
A written record of the outcome of any Strategy Discussion convened under the child protection procedures must be sent to all agencies invited to contribute, whether or not they did so.

OVERVIEW RECOMMENDATION 10
A professional working as part of a team e.g. within a Hospital or local authority, must ensure that they share the outcome of any meeting held under the child protection procedures with others in their agency who are working with the child and/or family

OVERVIEW RECOMMENDATION 11
All agencies who are members of the Safeguarding Board should ensure that their staff are aware of the need to appropriately share information where this is necessary to protect children. Section 28.2 (a) of the Children Act 2004 would permit this[8]

OVERVIEW RECOMMENDATION 12
The Chair of the Local Safeguarding Board should write to the Welsh Assembly Government to draw their attention to the difficulties experienced in this Review in obtaining information about the parent's medical history thereby reducing the opportunity of learning from the case

OVERVIEW RECOMMENDATION 13
The Chair of the Local Safeguarding Board should write to the Welsh Assembly Government to request that they consider providing specific

[8] Each body to whom this section applies must make arrangements for ensuring that their functions are discharged having regard to safeguard and promote the welfare of children

guidance on the criteria to be used in deciding whether an agency provides a separate Review or participates in a single agency review.

OVERVIEW RECOMMENDATION 14
The Chair of the Local Safeguarding Board should send a copy of the Overview to the Chair of the Local Safeguarding Board in whose area Hospital 3 is located.

CONCLUDING COMMENTS

66. This was a very unusual and complex case to review. It is unlikely that a similar combination of EB and FII will recur. However, that should not detract from the need to learn from the experience since there are many lessons which could apply more widely.

67. The recommendations that the individual agencies made, together with those added by the Review, should help address the many issues that have been raised and improve the quality of practice.
