



Norfolk Safeguarding Children Partnership

Norfolk Safeguarding Children Partnership
Serious Case Review
Child AE
September 2020

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Executive summary

This SCR concerns the tragic death of a young man. Norfolk Safeguarding Children Partnership (NSCP) extend their sincere condolences to all members of his family for their loss.

Every child, young person, adult, and family are unique. Child AE and his family were no exception to this rule of life. That said, Child AE and his family faced more than the average amount of challenges.

Child AE had complex physical and emotional needs; this meant there was a wide range of multi-agency clinicians, professionals, teams, and services involved and their involvement was governed by a great deal of legislation, practice & clinical guidance, policy, and procedure. In this complex landscape, it was difficult to achieve consistent multi-agency collaboration and this had a significant impact on achieving a holistic approach.

The key findings of this SCR focus on the need to:

- Appreciate the particular challenges faced by adolescents
- Celebrate the importance of ordinary life
- Think family
- Recognise the impact of isolation and take action
- Support family members and multi-agency staff in their attempts to provide the best possible care to vulnerable young people so that their potential can be fully realised.

Regretfully, these findings are not unique to Child AE nor are they unique to Norfolk. Eminent authors, theorists and experts have attempted to understand many of the issues raised in this SCR. Their work has been used in an attempt to understand what may have been below the surface of the multi-agency response that contributed to the difficulties identified.

NSCP have accepted the findings of this report in full and work has already commenced in an attempt to improve the multi-agency service response to children and young people in Norfolk, but there is more to do. This SCR raises important questions about how the system will continue to learn and adapt to enable an improved response to children such as Child AE.

NSCP are thankful to Child AE's family and the professionals involved for their contributions to this SCR.

Introduction

This Serious Case Review (SCR) concerns a 16-year-old child (Child AE) who sadly died. There had been multi-agency involvement with Child AE for a number of years. Child AE was never the subject of statutory safeguarding intervention but was known to multiple services, professionals, and clinicians as a result his complex emotional and physical needs.

Norfolk Safeguarding Children Board (now Partnership)¹ decided that the circumstances of his death met the criteria for a Serious Case Review (SCR). This SCR has involved the agencies and professionals who worked with Child AE and family members. It was commissioned in addition to the statutory processes followed by the Local Authority Designated Officer, the NHS, and the Coroner; these parallel processes have now been concluded.

Parallel processes

The inquest into Child AE's death has concluded that Child AE's death was *due to natural causes contributed to by a paracetamol overdose*. The coroner expressed a number of concerns about the services Child AE received towards the end of his life and made a number of recommendations. A Root Cause Analysis Investigation Report was completed by the relevant Clinical Commissioning Group² and provides a review of the services provided by the acute hospital, the relevant mental health trust, and the ambulance trust during the week preceding Child AE's death.

Significant learning has been identified in this report and by the coroner for all NHS trusts. It was understood that work is underway to address this learning. Additional processes included an education tribunal, where the judge made a number of orders about local services, and involvement by the Local Authority Designated Officer (LADO). The latter came about as a result of an allegation made to the police by the parents of Child AE relating to a professional involved in Child AE's care after his death. Although the allegation did not result in a charge, the LADO was required to assess any necessary changes in child safeguarding arrangements pertinent to the professionals work in light of the allegation. At the point of finalising this report it is unclear how these matters were concluded, Norfolk Safeguarding Children Partnership (NSCP) are committed to continue in their attempts to seek assurances that the relevant issues have been properly dealt with and to address any learning arising.

This SCR will not repeat nor re-investigate areas already covered by these processes nor will this report investigate culpability. As highlighted within current guidance:

¹ Under the Children & Social Work Act 2017 and Working Together 2018 Local Safeguarding Children Boards were replaced by local safeguarding partners who are required to co-ordinate their safeguarding services; act as a strategic leadership group; and implement local and national learning, including from serious safeguarding incidents.

² Root Cause Analysis Investigation Report. West Norfolk Clinical Commissioning Group 8.5.19

They (Reviews) are not conducted to hold individuals, organisations, or agencies to account, as there are other processes for that purpose, including through employment law and disciplinary procedures, professional regulation and, in exceptional cases, criminal proceedings.³

However, it is important to note that during finalisation of this SCR Child AE's parents told the author that they had not been informed as to why there had been involvement by the LADO, nor had they received communication from the responsible agencies about how the orders from the Education Tribunal (or the recommendations from the Root Cause Analysis Investigation and the Inquest) had been taken forward. Norfolk Safeguarding Children Partnership attempted to seek assurances from responsible parties that the required action had been taken and urged services to communicate with Child AE's parents. However, at the time of concluding this SCR these issues had not been fully resolved and is addressed at the end of this report.

Purpose of this SCR

The purpose of a SCR is to seek to understand what happened and why it happened in the context of local safeguarding systems, rather than solely the actions of individuals, and to ensure that agencies are held accountable for their services, systems and processes in safeguarding children and how they work together as a multi-disciplinary system. SCRs also aim to enable Local Safeguarding Children Boards/Partnerships to test the effectiveness of local and national safeguarding children procedures, protocols and working arrangements and to inform future service improvements through the detailed review of a single case.

Principles

- The multi-agency safeguarding system is a complex system: when trying to create the safest possible system, there are no quick fixes and no easy answers.
- Over time, SCRs have often repeated similar messages about the learning and the actions required.⁴ A new set of procedures, policy, training, staff development or new initiatives, in isolation, will not create safety.
- Systemic approaches alone, do not sufficiently get beneath the surface of the complexities. The safeguarding system is fundamentally a human system and the emotional experience of individuals, organisations and systems are an important feature of how services are provided, and safety achieved.

³ Working Together to Safeguard Children Chp.4 DfE 2018

⁴ Complexity and challenge: a triennial analysis of SCRs 2014-2017. Final Report. March 2020 DfE

- SCRs should involve learning throughout the process and across the hierarchies with those who are working in the system and those who are receiving services. Frontline staff, children and families are best placed to identify vulnerabilities and strengths.

Methodology

The review was led by an independent lead reviewer⁵ and an independent consultant⁶ was commissioned to author the report; the author received external supervision.⁷ The timeframe for this SCR is two years and seven months, it starts when the Local Authority received a complaint from Child AE's parents and concludes just after Child AE's death.

A panel, made up of relevant agencies in Norfolk who had no prior involvement with Child AE's case, were fully engaged throughout the review. A vast amount of documentation was reviewed and analysed by the Lead Reviewer. The Lead Reviewer and the panel had individual meetings with 30 practitioners/clinicians and managers who had been involved in providing services to Child AE. A meeting took place between Child AE's parents and the Lead Reviewer at the start of the review and at the end of the review meetings took place with Child AE's parents to share the final report. These meetings have informed this report.

It is important to acknowledge the views of family members and professionals were expressed with the benefit of hindsight. That said, their views remain pertinent.

Report Structure

This SCR will not provide a detailed account of the multiple services and interventions in this case. Instead, this review has attempted to focus on the totality of the different services provided, the impact on Child AE and his family and other young people like him. Whilst current guidance supports this approach, the decision for taking this kind of approach came from the meeting between the Lead Reviewer and Child AE's parents at the start of this SCR. During this meeting they reflected on the multi-agency involvement with their son, and on many occasions expressed their concerns that : *No-one was looking at the whole.*

Each agency involved in providing services to Child AE and his family have reviewed the services they provided, and action is being taken to address areas that require improvement. This SCR is focussed on multi-agency learning and will identify learning and make recommendations relevant to whole multi-agency system. In line with current guidance, any systemic or underlying reasons why actions were taken,

⁵ Jane Held : Director Jane Held Consulting Ltd.

⁶ Bridget Griffin: BA (Hons) CQSW, MA, Accredited SCIE Lead Reviewer

⁷ External Supervisor : Vega Zagier Roberts MD

or not taken, in respect to matters covered by the report, have been analysed and a summary of recommended improvements is provided.

Summary of service involvement and key learning

The following is a summary of the key learning in this case. Where it has not been possible to fully evidence the systemic nature of the issues on a local level, relevant national research is referenced. At the outset it is important to be clear that this review has found that no one action or collection of actions or inactions by professionals or family members resulted in Child AE's death. However, this view is not shared by Child AE's parents. Their view is that the inaction and action of professionals shortly before Child AE's death directly caused his death. This was not the finding of the inquest although the coroner identified a number of significant concerns about the services provided shortly before Child AE's death. This review will not repeat these concerns; the relevant agencies are fully aware of the changes they are expected to make and there is no question that these changes must be made.

It is equally important to be clear that there were opportunities to make changes in the way services were provided that could have significantly improved Child AE's quality of life and a number of examples are provided in this report. Of particular importance was the lack of action to address the impact of isolation on Child AE's wellbeing, the fragmented approach across and within agencies and the lack of unity between professionals and parents which would have compounded his feelings of isolation.

Taken as a whole, there was some considerable variation in how professionals followed policy and procedure; some professionals were fully compliant whilst others were not. It is not possible to say that at every point everybody did the right thing. However, it is possible to say that Child AE was much loved by his family, and the vast majority of professionals appeared committed to providing a good service. Alongside the areas of learning detailed in this report, there was also evidence of good practice by professionals/clinicians and there were many occasions when the commitment of Child AE's parents to secure the best possible services for their son was clear.

Overall, the response to Child AE starkly illustrates that whilst government guidance policy and procedure could understandably lead to an assumption that the multi-agency services provided to children is one unified 'system', it is not. It is a collection of various complex systems held loosely together under some shared legislation, policies and procedures aimed at safeguarding children. However, this SCR highlights that within this multi-agency landscape there is a wealth of statute, policy and guidance that is particular to specific services which may not be routinely shared. For practitioners and clinicians on the front line, finding a pathway through this labyrinth for the benefit of a child can be extremely difficult.

It was clear that the emotional challenges faced by parents and practitioners on the front line, who are trying to achieve the best possible outcomes for some of our most vulnerable children, is immense. The collateral damage caused by these emotional challenges coupled with the frustrations of working in an imperfect system should not be underestimated.

Leadership and governance of this 'system' is the responsibility of Norfolk Safeguarding Children Board⁸ but the reach, resources, buy in and ownership of this Board/Partnership is continually evolving, and this adds to the difficulties of providing an integrated multi-agency response at the front line.

And, in cases such as this, when multi-agency professionals and clinicians are working without the involvement of Children's Social Care, important questions are posed about ownership: Who holds accountability, leads, and contains the work? How is an integrated multi-agency response achieved? This case and others illustrate that this is often exceedingly difficult to achieve and in this imperfect system there is no doubt that cracks and splits will emerge, children, families, professionals, and clinicians will experience this and as a result there may be understandable fragmentation, frustration and anger.

The key learning from this SCR highlights the importance of achieving an integrated multi-agency response. It explores how the emotional impact of the work can contribute to the challenges of providing a holistic response in a fragmented system. The review identifies that a child and family's needs must be seen and met within a holistic framework and asks how a child's basic, but fundamental, needs can be honoured and met.

The next section of this report explores the key learning in the following areas:

- **Section one** highlights the importance of ordinary life in human development particularly when life may be dominated by medical intervention and mental health needs.
- **Section two** focusses on the particular challenges faced by adolescents and the challenges faced by professionals when attempting to balance the wishes and feelings of young people whilst safeguarding their welfare.
- **Section three** explores care planning, multiple pathways and processes and the lack of integration that can occur.
- **Section four** recognises the importance of family life, the interrelated and dynamic needs of members and the need to 'Think Family'.
- **Section five** explores the impact of multiple complaints on children, families, professionals and service provision and urges 'just learning cultures' to be established to improve service delivery.

⁸ Now: Norfolk Safeguarding Children Partnership

Summary Timeline

- The following is a summary of events during the period covered by this SCR. Not all incidents are included, its purpose is not to provide a detailed account but to provide a broad picture of events.
- The timeline starts when Child AE was thirteen and ends when he tragically died, shortly after his 16th birthday.

May 2015 Child AE Aged 13	Child AE had barely been in school since the beginning of the year. There was an ongoing dispute about how Child AE's non-epileptic seizures were managed in school & there was no plan to secure his reintegration.
October 2015 Child AE Aged 14	Child AE remained out of school and there continued to be no agreed plan to secure his reintegration. Educational Psychology report identified Child AE had recently disclosed increasing identification with the male gender and recommended referral to CAMHS for anxiety and depression and reintegration into school.
January 2016	Child AE remained out of school and there continued to be no agreed plan to secure his reintegration. Two hours of 1:1 tuition (daily) had been commissioned by the LA and the Education, Health and Care plan (EHCP) had commenced.
April 2016	First appointment at CAMHS. Child AE placed on waiting list for allocation to a CAMHS coordinator
May 2016	Early Help Service accepted a referral to the team to offer support to the family.
October 2016 Child AE Aged 15	CAMHS review – Child AE remained on waiting list for CAMHS coordinator. Decision to refer for family therapy
Nov 2016	First appt at Great Ormond Street Hospital (GOSH) – diagnosis of autism. First appt at The Tavistock Clinic Gender Identity Development Service (GIDS). First Tier Tribunal SEND & Disability decision reached: serious instances of disability discrimination by the school and actions of other agencies criticized.
Jan 2017	Child AE remained out of school and there was no agreed plan to secure his reintegration. Attended GOSH 3-day intensive CBT for social anxiety. Anti-depressants prescribed & recommendations included: ongoing CBT - to be provided by local CAMHS & a specialist school place Second appt. GIDS. First appointment with CAMHS Care coordinator
March 2017	Third appt. GIDS
April 2017	First Family Therapy session
May 2017	Admitted to a general hospital – concerns about Child AE's food intake and mental health. Transferred to T4 Inpatient Unit 14 days later.
July 2017	Child AE remained an inpatient at T4 Unit. Mental health assessment completed & Child AE formally admitted under Section 2 of the Mental Health Act (MHA) End of July : Increasing parental concern about the unit's ability to provide for Child AE's autistic needs led to a decision to transfer Child AE to an alternative unit

August 2017	Child AE : 11 weeks in T4 Unit. Transfer to alternative T4 Unit not progressed - Section 2 of MHA rescinded and Child AE returned home for a week's trial then formally discharged
September 2017	First visit by Eating Disorder Practitioner.
October 2017 : Child AE Aged 16	Parents reported increasing concern about Child AE's eating and mental health.
November 2017	Referral to Multi-Agency Safeguarding Hub by Early Help & CAMHS due to concerns about Child AE and family wellbeing and ability to keep Child AE safe. Child AE attended CAMHS appointment and informed clinician of paracetamol overdose. Child AE tragically died in hospital

Key Learning

1. Valuing the importance of everyday things

i. Ordinary Adolescent development

Brain development: Adolescence is one of the most dramatic stages of life development. With the onset of puberty come bodily changes such as spurts in growth and the development of the sexual organs, as well as changes in the neurobiological system focused on emotions and social interaction.

These changes underpin mid-adolescents' sensitivity to emotional cues⁹ as the specific region of the brain known as the amygdala, which is associated with emotions, impulses, aggression, and instinctive behaviour, is increasingly relied upon to make decisions, and solve problems. In contrast, the neural systems that underlie the complex cognitive abilities involved in control and regulation develop very differently, maturing gradually over the course of adolescence and into young adulthood : *The adolescent brain goes through a rapid process of developing new neural connections and this process is fundamentally shaped by social interactions and relationships – thus contributing to this life stage as one that offers a significant window of opportunity.*¹⁰

Personality Development: One of the best-known theories of personality development was put forward by Erik Erikson.¹¹ Erikson argues that there are eight stages of personality development and our psychosocial development is organised under a number of distinct stages. The fifth stage of Erikson's theory is identity vs. role confusion, and it occurs during adolescence, from about 12-18 years. During this stage, adolescents search for a sense of self and personal identity through an intense exploration of personal values, beliefs, and goals. They are becoming more

⁹ Steinberg, 2010; Dreyfuss et al, 2014

¹⁰ That Difficult Age: Developing a more effective response to risks in adolescence Dr Elly Hanson and Dez Holmes. Dartington 2014

¹¹ Identity and The Life Cycle. E. Erikson. USA (new edition published 1994)

independent, begin to look at the future in terms of career, relationships, families, housing, and there is a strong desire to belong, and fit in.

At this time of life, role models and peers are of central importance and a sense of self is developed primarily through social relationships. If these opportunities are not available, adolescents can become confused about their self-value and their place in life.

Research in Practice¹² suggests that the pathways leading to a number of harms that adolescents experience are complex, not least because they often involve adolescent choices and behaviours. At times, these choices relate to the influence of specific developmental processes. For example, the adolescent stage of development involves increased risk-taking, emotional highs and lows, and sensitivity to peer influence, all underpinned by interacting social and neurobiological changes. These factors can play into risks such as self-harm

*The evidence we draw on in this scope, both research knowledge and practice knowledge, can and should encourage us now to re-design the system in a way that 'works with the grain' of adolescent development, takes a more nuanced approach to risk identification, has relationships at its heart, and is focused on building resilience.*¹³

ii. Making space for ordinary life

Prior to the start of the review period, Child AE was a young person who was attending school and doing well. He was a bright young person who was ambitious and was clear about the career he wanted to pursue. Child AE attended school regularly, he had friends and was regarded as 'bright' and as someone who would do well. Child AE very much enjoyed being at school and he regularly attended Scouts where he participated in a range of activities. Child AE was open when discussing that he was uncomfortable about his assigned birth gender and at the age of 15 years he was clear that he wanted to be referred to by the male pronoun. This SCR honours this wish.

During the period under review, Child AE's circumstances changed. By the end of his life 10 different medical diagnoses had been made and over 80 professionals were involved. He had been an inpatient in a Tier 4 mental health establishment suffering from an eating disorder and high levels of self-harm. He was not attending school or scouts and much of his life was spent at home with his mother. This isolation had a significant impact on all aspects of Child AE's life, as identified by Child AE's parents: *He was with [name of mother] 24 hours a day. He had no real engagement with anybody outside this house so had just become more and more*

¹² Research in Practice is a 'not-for-profit' organisation that exists to support the children and families sector, by embedding evidence-informed practice at all levels of an organisation

¹³ That Difficult Age: Developing a more effective response to risks in adolescence. Research in Practice Dartington 2017.

isolated.....He became so isolated that he couldn't even leave the house.....The isolation was the big, big problem.

From the various documents reviewed and the various conversations with professionals/clinicians and family members, through no fault of their own, what emerged was a picture of a child who was increasingly isolated and whose identity was defined by his diagnoses.

All about me – my story so far. My Name is and I am 15 years old..... I suffer from Non-Epileptic Attack Disorder and Anxiety. I have seen a Doctor who says I have Autistic Spectrum Disorder. I have other health issues too.¹⁴

It seems that what got missed was the human element of seeing Child AE as an ordinary young man. His attendance at scouts was a good example of a space where this was more possible. By making every effort to accommodate Child AE's needs, the Scout Group were able to create a place where Child AE belonged; he was just a teenager, engaging with other teenagers doing ordinary things, where his medical labels did not define him. But increasingly Child AE was in the role of patient for much of the time and towards the end of his life there seemed to be no space for him to be healthy – just to be himself- an adolescent who was facing the challenges presented by this particular stage of human development.

iii. Being human: The Human Condition

Child AE was seen, assessed, and treated by a wide range of clinicians. He had been diagnosed with Autistic Spectrum Disorder and gender dysphoria, non-epileptic seizures, functional hemianopia, Irlen Syndrome, Raynaud's Disease, anorexia-nervosa, depressive disorder, and anxiety disorder. Treatments and therapeutic interventions were provided by local services, although on at least one occasion left uncompleted with a lack of clarity as to why this was the case. In addition, Child AE spent 11 weeks as an inpatient in a Tier 4 mental health establishment and received treatment from The Tavistock Clinic and Great Ormond Street Hospital in London.

In this section of the report the question that arises is whether it was possible to hold onto simpler concepts about what is needed to promote psychological wellbeing.

*There is only one mental condition, the human condition..... By switching from an emphasis of treating mental conditions to meeting the needs of the human condition, stigma could be reduced, and a positive and normalising vision could be offered.*¹⁵

In 2006/7, a group of eminent psychological thinkers¹⁶ advised the Secretary of State on the universal psychological needs of the human condition. Five fundamental needs were agreed:

- *to be loved,*
- *to be heard,*
- *to belong,*

¹⁴ Quote from Child AE contained within his Education Health and Care Plan

¹⁵ M. Seager. The British Psychological Society. The Psychologist. April 2017 Vol.30 (PP. 66-67)

¹⁶ Including but not exclusive to M. Seager, P. Kinderman & L. Johnstone

- to achieve,
- to have meaning and purpose

To be loved and heard: It was clear that Child AE was loved by his family and there were many occasions when professionals and family members heard his wishes and feelings and took action. On occasions, this led to conflict between professionals and family members and between professionals. One of the main reasons for this conflict was the question of whether, when and how, his consent/wishes and feelings and/or that of his parents could and should be overridden. This is explored in Section 2 which focusses on safeguarding adolescents.

However, there were three clear areas of his life where Child AE regularly expressed his wishes: to be referred to by the male pronoun, to be in school and for family therapy to be consistently provided. These last two wishes were not realised throughout the duration of the review period. Section 4. explores family therapy and the lack of a school place is explored below.

To belong, to achieve, to have meaning and purpose. The isolation Child AE experienced through the last three years of his life, caused primarily by the lack of a school place, meant that Child AE did not have a sense of belonging, achievement, meaning and purpose.

iv. The importance of school life

The importance of schools in the lives of children is well recognised and the impact on children of not being in school has been raised in Serious Case Reviews and government guidance. This is relevant for all children but especially vulnerable adolescents who may have complex mental health needs, may be at risk of exploitation, serious youth violence and/or self-harm. Yet these children are at greatest risk of being without a school place. Children with special education needs (SEND) are particularly vulnerable and this has been the subject of considerable media interest.

According to Guardian analysis of Department for Education statistics, just under 4,500 pupils with statutory rights to special needs support were awaiting suitable provision or being home-schooled at the start of the year.¹⁷

Child AE enjoyed being at school, he progressed well in his learning and development and enjoyed trusted relationships with staff. Whilst at school, Child AE suffered from many non-epileptic seizures and there was significant tension and considerable conflict between Child AE's parents and school staff about the best way of managing these seizures.

A number of attempts were made to find a resolution, but the relationship between school staff and parents became extremely difficult. The school attempted to gain the support of the Local Authority (LA), and other involved services, but were left feeling

¹⁷ <https://www.theguardian.com/education/2018/oct/23/send-special-educational-needs-children-excluded-from-schools>

isolated and at a loss to know how to navigate through the complexities. Eventually, it was decided by the school that it was not safe for Child AE to be in school and his parents concluded that unless the cause of his seizures at school was addressed, it was not safe for him to return.

During this time, Child AE's circumstances seemed to fall into a void. The complex relationship between the school (an academy) and the LA seemed to get in the way of finding a resolution and as a result neither the school nor the LA took accountability for securing his education. This left Child AE without a school place for an unacceptably long period of time. Child AE's parents appealed the lack of a school place through a Disability Discrimination Claim. The Judge found that there had been serious incidents of disability discrimination; reasonable adjustments had not been made to provide for Child AE's education at home and Child AE's health care plan had not been followed.

We regard these failings by the school as serious instances of disability discrimination. Put broadly, school completely failed to take into account (name of Child AE) 's position as a disabled pupil; and failed to give adequate weight to (name of Child AE)'s parlous position as a pupil who had already in practice missed two terms of education.....But in criticising the approach of the school, we also observe that few of the many agencies involved emerge with much credit.¹⁸

This SCR will not identify in detail the reasons for these findings. In summary, systemic failings were identified in the school and the Education Inclusion Service which at the time was overwhelmed, process driven and underdeveloped. It is understood that significant work has been done to restructure, improve capacity and capability and to deliver a transformation plan for children with high needs.

It was clear from agency documents and from the conversations with his parents and with professionals that Child AE had enjoyed being at school and wanted to be there:

He needed to be in school.....One day he sat there for about an hour, two hours crying solidly: 'I just want to go back to school' ¹⁹

Child AE's parents said that in the end they *gave up* and so did Child AE – *by the end he no longer wanted to go* [to school].

Schools are important not just for a child but also for the wellbeing of the whole family. It is one place that is open to all: it is a place where the only threshold criteria is age therefore it represents a non-stigmatising service. It is an environment where ordinary peer relationships flourish under the guidance of adults and where trusted

¹⁸ First- tier Tribunal Special Education Needs and Disability Decision. Mr H Forrest (Tribunal Judge) 9/11/16

¹⁹ Comment made by AE's mother during meeting with Lead Reviewer as part of this SCR

relationships with adults are formed. Schools can be a place where there is a sense of belonging and a place where aspirations for the future lie. On the other hand, the absence of a school place can present significant difficulties for children including, but not exclusive to:

- isolation from peers and trusted adults
- limited opportunities to develop important life skills
- a lack of exposure to adults/older peers who can be essential role models
- a thwarted sense of belonging
- a reduced sense of self-value and reduced hopes for the future

However, this does not mean that schools are without their own challenges. Like their multi-agency partners, they operate under specific statute, policy, guidance, key performance indicators and resource constraints and there is a frequent tension between meeting the needs of an individual child balanced with the good of all pupils.

In this climate, there is a need for the Local Authority, schools, multi-agency partners and parents to enter into partnerships together. These partnerships may involve challenging debate and inevitably, on occasions, compromise. What becomes of utmost importance is honouring the critical place occupied by schools in children's lives by all professionals and, in spite of the imperfect system, being open to negotiation and being persistent in finding a solution for the sake of the child.

Valuing the importance of everyday things: Conclusion & Recommendations.

Ordinary Adolescent development – making space for ordinary life. There is a need to recognise and celebrate the essence of the ordinary in children's lives allowing for the system of professionals, clinicians, and parents alike to provide a non-pathologising intervention, structure, and system to children, particularly during adolescence. It is understood that work is in progress within Norfolk Children Service (NCS) to develop a specific adolescent care pathway and Norfolk and Waveney Clinical Commissioning Groups (N&WCCGs) are currently redesigning services within the Child and Adolescent Mental Health Service. It is vital that this work recognises the critical place schools occupy in the life of a child and the potential impact on a child's mental health and wellbeing when they have no school place.

Recommendation 1: NCS and N&WCCGs to integrate learning from this SCR into current service developments and place sufficient emphasis on: the importance of ordinary life, adolescent development, schools and multi-agency consultation and collaboration. Collaboration to take place with the working group as identified in Recommendation 2 (below) to achieve a joined-up approach.

Norfolk Safeguarding Children Partnership (NSCP) to be informed of progress and provide challenge.

The importance of school life. School life provides a crucial platform where the critical components of healthy development can be nurtured. It is not just a place of academic learning; it is somewhere to belong, to achieve, to have meaning and purpose and is an arena for social and emotional development in preparation for adulthood. There is no single recommendation that can address this learning, it requires a culture shift both in terms of how multi-agency services value the multi-faceted benefits of school and a redesign of service intervention so that schools are placed at the very heart of multi-agency provision.

Recommendation 2: NSCP to establish a multi-agency working group, in partnership with senior leaders in schools, to determine how schools will be supported in placing school life at the heart of multi-agency provision for children with multiple and complex needs. Collaboration to take place with the work stream identified in Recommendation 1 to achieve a joined-up approach.

Norfolk Safeguarding Children Partnership (NSCP) to be informed of progress and provide challenge.

2. Safeguarding Adolescents

Various legislative frameworks, policy, procedure, and practice guidance detail the requirement to safeguard children and emphasise that this is the responsibility of all agencies. Safeguarding is a generic term; loosely translated, it means we are all responsible for promoting the welfare of a child to enable their potential to be realised. Safeguarding children is based on a continuum of need, at the highest threshold this involves taking statutory action to protect a child from significant harm.

i. Balancing wishes, feelings & welfare

There is a legal requirement to make decisions about a child that take account of their wishes and feelings and, as a child reaches adolescence, a child's right to privacy and their wishes and feelings must be carefully balanced with considerations about their welfare. One of the complexities of working with older adolescents is the issue of consent: Whose views dominate - the parent, the professional, or the child?

Taken as a whole, it appears that there was a desire to do what was best for Child AE and to take decisions by balancing his wishes and feelings with his welfare. There were times when concerns about his welfare rightly superseded his wishes and feelings, and this was in line with the requirements of The Children's Act (1989) but this Act was rarely used as a basis on which decisions could be made.

Child AE's wishes and feelings were sought throughout multi-agency intervention by a variety of professionals about a variety of matters. When necessary, health

professionals referred to The Gillick²⁰ competency guidelines or made an assessment under the Mental Capacity Act about Child AE's competency to make an informed decision. The view of Child AE's parents was that these decisions were *made in the wrong context, under the wrong time under the law and excluded Child AE's autism diagnosis* and were used as a way of dispensing with parental consent. This led to significant conflict with mental health professionals.

Making decisions about the care of children who have significant mental health difficulties, can be difficult. There is a need to balance a child's wishes and feelings with their welfare whilst also considering the views of those who hold parental responsibility. When achieving this difficult balance, there will be times when the decisions reached will be in opposition to the views of a child and/or their parents. As a result, feelings of anger and frustration may surface.

Whilst the guidelines and statute used by health professionals were appropriate terms of reference, making a decision that may be in opposition to a child's (or a parent/s) wishes and feelings is also covered under The Children Act 1989. This legislation is the primary legislation that can be usefully referenced in these circumstances, as under this legislation and associated guidance²¹ the safeguarding of a child is the paramount legal principle.

In the meeting with Child AE's parents, as part of this SCR, they spoke about the need for someone to take responsibility, make difficult decisions and be clear about these decisions (even if these decisions were not in line with parental views) and gave examples of clinicians who demonstrated this approach. It was the view of Child AE's parents that if decisions about Child AE's care and treatment consistently featured this approach (and they were clearly informed that the decision was being made in their son's best interests), they would have been more likely to accept the decisions that were made. This position is both understandable and reasonable.

The perception of some professionals, who were involved at this time, is that this understandable and reasonable position was not a feature of their relationship with Child AE's parents. It is clear that some professionals were able to engage with Child AE's parents in a respectful partnership for the benefit of Child AE; on the other hand, some of the interaction between professionals and Child AE's parents could be highly charged and fraught with conflict. These difficult dynamics were an enduring feature of the relationship between mental health professionals and parents, particularly when Child AE was an inpatient. It was crucial to find a way to improve this relationship for the sake of Child AE, but little progress was achieved. This is discussed further in Section 5.

²⁰ The Gillick competency guidelines help people who work with children to balance the need to listen to children's wishes with the responsibility to keep them safe.

²¹ Working Together to safeguard children DFE 2015 & 2018

ii. Statutory Safeguarding

During the period under review concerns about difficult familial relationships (and the impact on Child AE's emotional wellbeing) were raised and referrals to Norfolk Children's Social Care (CSC) were considered. What emerged was a distinct split between professionals about whether Child AE was at risk of significant harm. This split remained unresolved throughout the entire period under review and persisted during the discussions held as part of this SCR.

On an occasion when Child AE was an inpatient, a referral was made to CSC. CSC concluded that the concerns did not meet the threshold for a child protection response and, as the family were working with the Early Help Team, there was no need for additional services to be provided. The referrer was advised that should parental co-operation with the Early Help Service decline, a further referral should be made.

Child AE spent 11 weeks as an inpatient with a further week spent at home prior to discharge. The circumstances of his discharge were challenging for all but particularly Child AE as it involved heated disputes between parents and staff about whether he was ready to return home and little time to prepare for his transition. Staff told the author of this SCR that Child AE said he was not ready to return home at this time, but it is also clear that he told his family that he was. This was not the only time Child AE was caught in the middle of the conflict between those responsible for his care. There was a need for services to provide a high level of support to the family at this difficult time. However, several problems were identified by the coroner about the involvement of services over this period which included the absence of a written up to date care plan and the unacceptable delay in the involvement of the eating disorder service. In her conclusions, the coroner spelt out areas of service development that were needed.

There are particular risks during transition from an inpatient unit to care in the community and these risks were not fully understood or mitigated. The reason for this is partly because this discharge was planned at short notice, however, it is important to acknowledge that little was put in place thereafter.²²

At the point of Child AE's discharge, Children's Social Care (CSC) took the view that as parents were co-operating with the Early Help Service, and there were no immediate child protection concerns; they had no role in the case.

Three months later, professionals in CAMHS and the Early Help Service were increasingly concerned about Child AE and on the day before Child AE took an overdose, professionals discussed with Child AE's Mother and Child AE their intention to refer to CSC. Child AE's parents were also concerned about Child AE's

²² The Report by the Coroner explores this area of service provision & makes recommendations therefore no specific recommendations are made in this SCR.

wellbeing and that evening attempted to elicit support by contacting the relevant mental health crisis team.²³ On the day Child AE was admitted to hospital, after taking an overdose, the referral was accepted by CSC.

By this point, the family had been receiving services from the Early Help Service for some time. This service supported a referral to CSC on the basis that the family had reached crisis point and required additional support. It was the view of the Child and Adolescent Mental Health Service (CAMHS) that the family were finding it difficult to provide the right level of support and that there was evidence that the high emotions in the household had a direct impact on Child AE, possibly increasing his fears and leading him to feel unsafe.

It seems to the report author that after some considerable period of disparity across the multi-agency network, about whether or not a referral to CSC should be made, a semblance of an agreement had been reached. However, neither referral gave enough information to suggest that a child protection response was required. Even if there had been more information to suggest that Child AE was suffering significant harm, the question that needed to be asked was: How would the involvement of yet another service make a discernible difference to Child AE?

There is no doubt that relationships at home could be difficult (this was acknowledged by the family and had been identified by a clinical psychologist almost 3 years previously). There is also no doubt that caring for Child AE's complex needs placed a significant strain on the family: Child AE had been without a school place for over three years, little education had been provided, little family therapy had been offered, there had been delays in the provision of required treatments and his parents were desperately worried about Child AE's mental, physical, emotional, social and educational wellbeing. These collective anxieties and needs would have coalesced, creating a home environment where there was significant tension.

However, in the view of the report author, the purpose of this referral and the outcome intended was unclear. If the intention had been to facilitate a multi-agency response and a lead professional (in the form of a social worker) this intention was laudable but not necessary. There were many were professionals within the network that could, and should, have taken up this role.

Countless SCRs reveal that co-ordinated multi-agency working beneath the threshold of statutory safeguarding is vital, yet this remains difficult to achieve. However, in reality, too often there is no 'magic wand' in the form of another service, another professional or another resource that can make a fundamental difference. There is a need to question whether involved services may be playing a part in contributing to familial tension and to be mindful that the involvement of statutory safeguarding services can result in the unintended consequence of contributing to household tensions.

²³ There was no direct intervention by the team at this time.

The work by Research in Practice on adolescent development (referred to above) and their more recent guidance about contextual, complex and transitional safeguarding is relevant.²⁴ On first look this guidance does not neatly fit with Child AE's experiences as this guidance and other associated guidance from Government²⁵ is focussed on risks within the community. But a central point in this guidance is that adolescents require a different approach than traditional safeguarding approaches and services need to be mindful that adolescents are likely to be cautious about services which they perceive will destabilise their established strategies for coping with their problems.

Safeguarding Adolescents : Conclusions & Recommendations

Balancing wishes, feelings, and welfare: As raised earlier in this report, there is a complex legislative and policy framework within which clinicians and practitioners must make decisions and this is starkly illustrated when making a decision that may be against a child's or a parent's wishes. In these circumstances, the different legislation, policy, and guidance can cause confusion. This case has shown that there is a difficult balance to be struck and making these decisions can be extremely problematic (particularly when there is considerable anxiety about a child's wellbeing). Without clear guidance, tensions will undoubtedly emerge.

Recommendation 3. Senior Managers from across the multi-agency partnership to discuss and conclude what is needed to support front-line practitioners, clinicians and managers to navigate this complex legislative landscape so that they can successfully balance the child &/or parents' wishes and feelings with the child's welfare and make clear defensible decisions.

NSCP to be informed of progress and provide challenge.

Statutory safeguarding. Safeguarding adolescents requires an approach that is mindful of this particular area of development, is cautious about actions that may destabilise existing coping strategies and is realistic about the benefits to the child and family of involving statutory safeguarding services.

Recommendation 4. The principles contained within the recent government guidance about contextual safeguarding should apply to all vulnerable adolescents.

NSCP to maintain an overview of how this will be implemented and how multi-agency staff will be supported to understand and apply this approach.

²⁴ Safeguarding during adolescence – the relationship between Contextual Safeguarding, Complex Safeguarding and Transitional Safeguarding C. Firmin, J. Horan, D Holmes G. Hopper. Research in Practice 2018

²⁵ Working together to safeguard children DfE 2018, paragraph 33 – 37

3. Care Planning

A review of the multi-agency chronology during the period under review showed that Child AE was the subject of 50 different medical referrals for a wide range of reasons. There were:

- 12 ambulance call outs, 11 of which were in response to non-epileptic seizures.
- 20 recorded non – epileptic seizures; and
- 15 hospital admissions.

Child AE had at least 10 different medical diagnoses and at various times was depressed and anxious, self – harming, hearing voices, experiencing visual and auditory hallucinations, not eating, not sleeping, neglecting himself and having suicidal thoughts. Child AE's mother told the lead reviewer that towards the end of his life Child AE was taking over 30 tablets a day.

i. Parallel processes and pathways

As identified at the start of this report, this SCR was conducted whilst other parallel processes were in progress. These processes do not fit neatly together, and this can cause duplication and delay. This was mirrored in the multi-agency response to Child AE and his family. In the last months of Child AE's life there were four different planning frameworks operating at once:

- Care Programme approach
- Care, Education and Treatment Reviews
- Education, Health and Social Care Plans
- Family Support Plans (Early Help)

Attempts to coordinate across these four systems were made but were unsuccessful and despite at least 26 multi-agency meetings with parents, during the period under review, there was little integration between these approaches; there was no one person in charge of Child AE's care and treatment and no evidence of a holistic approach.

When the Lead Reviewer met with Child AE's parents and explained this SCR, and the parallel processes, his father reflected on these processes and the processes that Child AE and family had experienced during multi-agency involvement. He made the following observation:

All the individual bits that are being done are all interwoven, but no-one is looking at that and no-one's looking at the consequences of everything as it's.....as it rolled on.

ii. Medical Pathways

Taken as a whole it is clear that Child AE's life, and family life, was dominated by Child AE's complex emotional and physical needs. His treatment and care followed

a medical model of intervention which was essentially linear;²⁶ there was no holistic view of Child AE's needs, no holistic plan to meet these needs and no one was 'in charge'.

Everyone worked in their own little silos one of the biggest problems all the way through is everyone seemed to have tunnel visionthey just wanted to continue standing at their boundary.²⁷

There was evidence of some good interprofessional and interdisciplinary communication. However, multi-disciplinary and multi-agency co-operation and collaboration between professionals, services and with the family, was inconsistent and at times problematic. The reasons for this are complex and include the following:

- A dominant medical model/approach that was piecemeal, with no review of all the parts
- The vast range of NHS providers/services
- The involvement of multiple professionals/clinicians
- Application of multiple policies, procedures, legislation, and clinical guidance
- Multiple treatment locations
- Different commissioning arrangements
- The lack of a lead professional with overall accountability
- The organisational and professional response to the frequency of complaints made by Child AE's parents (this is discussed in Section 4.)

The parents also raised questions about oversight of the medications prescribed by various health providers. The NSCP has commissioned a separate pharmaceutical review²⁸ to respond to these questions and this will be shared with parents.

iii. Complex presentations

In a desire to find answers to the array of Child AE's needs, Child AE's parents frequently sought referrals to specialists, experts, and services. Frustrated by a lack of observable improvement (or deterioration) and in a desire to get the best service for their child, they often complained.

Overall, the majority of Child AE's medical diagnoses and conditions had a direct link to an emotional source (such as non-epileptic seizures) or had possible consequences for his emotional wellbeing (such as autism). Whilst mental health services from Tier 3 & 4 CAMHS were clearly concerned with Child AE's mental and

²⁶ Put simply : See, diagnose, treat, and refer on.

²⁷ Comment made by Child AE's mother at the meeting with the lead reviewer

²⁸ *Following publication the decision was made to decommission the pharmaceutical review as it was outside of the NSCP remit. Such a review would be a 'single agency' investigation that should be carried out with appropriate access to the medical practitioners concerned and the medical records.*

emotional wellbeing, there was no collective consideration of what the primary aetiology for his collection of diagnoses, conditions and symptoms may have been.

And, importantly, whilst Child AE's autism was known about (as was the length of time Child AE had been out of school), there was little evident consideration of how these issues impacted on, and compounded, his mental health difficulties and little collective action to address these important issues. As a result Child AE was not seen as a whole person and the overall service response was characterised by fragmentation.

After reviewing the case documentation, and meeting with over 30 professionals and clinicians, the Lead Reviewer made the following comment: *Everyone involved has found much of this Review challenging and perplexing.....It also mirrors how NHS professionals described what was happening in terms of AE's health (i.e. perplexing presentations).*

The term 'perplexing presentations' was not used by professionals at the time they were working with Child AE and, whilst this concept has some value, it should be treated with caution. Ascribing terms per se can be unhelpful and potentially represents another attempt to find a label, or a diagnosis, to define the best fit for an unusual situation. This appears to mirror the approach to Child AE in that attempts to manage his needs took the form of dividing his needs into non-perplexing parts (for which there were answers).

In the view of the report author there was a need for all services and professionals to:

- Consider the needs that existed within the whole family
- View Child AE's different medical diagnoses and conditions in their entirety
- Be curious about the possible emotional causes
- Consider the systemic interactive impact of the various medications on his health and wellbeing
- Consider that when Child AE's presentations were viewed as a whole, they were difficult to understand.

The concept of 'perplexing presentations' is relatively new. Whilst the associated guidance does not neatly fit Child AE's experiences (as the concept is linked to fabricated illness which was not identified in this case) the recommended approach is a helpful aide memoire in these circumstances as it identifies the need for a lead professional, places the child and the family at the very heart of service provision, and provides a holistic response.

iv. **Responding to non-epileptic/dissociative seizures²⁹**

²⁹ Non epileptic attacks look like epileptic seizures but are not caused by electrical activity in the brain. The condition has several other names such as dissociative seizures, psychogenic non epileptic seizures (PNES), functional seizures or, fortunately used rarely now, pseudo-seizures.

As previously stated, during the period under review Child AE was diagnosed with multiple medical conditions. For the purposes of this SCR, it is neither proportionate nor helpful to explore these in great detail. However, it is important to consider Child AE's diagnosis of non-epileptic seizures as this condition led to a decision by his school that they were unable to meet his needs and had a significant impact on Child AE's quality of life.

Unlike epileptic seizures, non-epileptic seizures are not caused by physical disorders of the brain. Rather, non-epileptic seizures may result from traumatic psychological experiences or unusual stresses, sometimes even those in the forgotten past.³⁰

Child AE was allocated a specialist epileptic nurse who was actively engaged with the management of this condition, and in supporting Child AE and family members. It was clear that this nurse advocated for Child AE's needs, but it was equally clear that this condition was not widely understood by all clinicians or across the professional network. Consequently, education (the LA and the school) received little, and often conflicting, information.

NICE guidance³¹ states that, apart from considering a referral to a psychiatrist or psychologist, the same approach to epilepsies caused by electrical activity in the brain should be followed for non-epileptic seizures. The services provided by the epilepsy team were compliant with this guidance.

Given the differing aetiology, the NICE guidance appears to be somewhat limited in respect to this specific condition. The reason for this is unclear but may represent another attempt to turn something perplexing into something that is non-perplexing: something that is manageable, something that can be placed within an existing medical pathway.

It seems important that this condition is given some attention of its own, this is particularly important when considering prevalence:

Figures published for the United States in 2000 show "the prevalence of psychogenic non-epileptic seizures is somewhere between 1/50 000 and 1/3000, or 2 to 33 per 100 000, making it a significant neurologic condition".³²

Care Planning: Conclusion and recommendations

When faced with perplexing situations a normal response is to look for answers - to reach for certainty. When faced with a child with significant needs there is an understandable desire to find a solution – to make them better, and when this is not achieved - more attempts to find 'the right answer' will often be made. Facing the pain and distress of children, particularly when there appears to be no easy solution,

³⁰ <https://www.epilepsysociety.org.uk/non-epileptic-seizures>

³¹ NICE: Epilepsies: diagnosis and management. Published Jan 2017, undated Oct 2019
<https://www.nice.org.uk/guidance/CG137/evidence>

³² <http://www.nonepilepticattackdisorder.org.uk/non-epileptic-attack-disorder/>

undoubtedly leads to anxiety and emotions can run high. As a result, individual and collective defences may be erected to defend against the unbearable nature of this anxiety. This characterised the approach, and response, by professionals and parents alike and is explored in Section 5.

No one person/clinician/practitioner/manager could have possibly made sense of this alone. A carefully structured approach is required, led by an informed understanding of both the medical and mental health issues supported by a multi-agency forum to view a child's needs in their entirety. Multi-agency reflective supervision should be an essential part of any approach to support staff and allow space for thinking.

Recommendation 5. NHS providers to work collaboratively with multi-agency partners to ensure a lead person is identified for children and young people with complex health needs and/or special educational health needs and disability. Intrinsic features of the approach to include placing the child and family as central and provision of robust support to the family and the lead person.

NSCP to be informed of progress and provide challenge.

Recommendation 6. NSCP to be informed of the progress made by Norfolk County Council and the Norfolk and Waveney CCGs to transform the services to adolescents³³ and provide challenge.

Learning from this SCR to be reflected in any service redesign.

Recommendation 7. Norfolk Community Health & Care NHS Trust and Norfolk and Suffolk NHS Foundation Trust to develop a joint pathway for non-epileptic seizures that considers the specific aetiology of this condition and the work needed to provide a joint approach to treatment, case management and awareness raising.

NSCP to be informed of progress and provide challenge.

NICE to be informed of progress to assist in the development of national best practice guidance.

4. Supporting Families

Parenting is not easy. Whilst guidance, research and words of wisdom are available, nothing can fully prepare parents for the emotional challenges and tasks involved.

³³ In line with government guidance local authorities, county councils and CCG's are responsible for redesigning mental health and wellbeing services to children and young people. In Norfolk this is known as the 'Transforming Care Programme' which, amongst other issues, is intended to reduce fragmentation

Parenting and care taking roles are largely shaped by the parenting we received, our childhood experience of family life and our unique life experiences. It can be difficult to predict how these experiences may impact on the quality of parenting we may provide or how our own needs may interact with those of our children. We may have faced childhood adversity, suffered trauma that may be unrecognised and/or unresolved, and we may have particular needs of our own. We may be wounded by these experiences and this wounding can be lifelong. The, often unconscious and unintentional, result is that we can unwittingly pass this wounding on to our children.

i. Think Family

*The whole process should be family centred*³⁴

During this SCR, both mother and father spoke about their own needs; Child AE's mother spoke about her own emotional difficulties, anxiety and mental health problems and his father described himself as *quieton the autistic spectrum* and spoke about how he is *slow to anger but liable to major outbursts if things get too much*.

Child AE's mother was open about her needs and there were attempts to meet these needs through some service interventions. Whilst some practitioners and clinicians suspected that father may have autistic traits, there appeared to be little understanding of these needs as a whole, or about how these parental needs interacted with those of Child AE, and on the relationship between Child AE's parents and practitioners/clinicians.

'Think Family' is not a new concept; it has been the subject of local and national guidance for some time. It is a concept that embraces the practice principles of 'Think parent, think child, think family.'³⁵ In summary, this requires practice and service provision to:

- Identify and build strengths in families
- Recognise the needs of children and adults and the dynamic interplay between these needs in the context of their relationships and environment
- Recognise and promote resilience and help to build capabilities
- Provide services tailored to these needs.

Elements of this approach were seen in the interventions across CAMHS, the services provided by the Epilepsy Team and the Early Help Team. However, this was fragmented and too often Child AE's parents were not regarded as equal partners by the professional network when providing care to Child AE, and an approach of 'professionals know best' was evident. This was seen on several occasions including care plans not being shared with Child AE's parents but was

³⁴ Comment by Child AE's father during a meeting with the Lead Reviewer

³⁵ Think child, think parent, think family: a guide to parental mental health and child welfare. Social Care Institute for Excellence December 2011

most starkly illustrated at the end of Child AE's life when his mother's understanding of her son's needs, prior to his admission to hospital, was set aside and she was denied access to her son.

What emerged was a split between services and professionals where some professional approaches were regarded as promoting the needs of parents at the expense of Child AE, or as advocating for Child AE at the expense of the family. This split within the professional network, and between professionals and the family, compromised the quality of care provided and inadvertently compounded Child AE's isolation.

The ethos of the Early Help Supporting Families Service³⁶ is to work with the family within the conceptual framework of 'Think Families' and Signs of Safety (SoS).³⁷ The SoS approach has a well-founded evidence base and has been extensively evaluated as improving outcomes for children. This approach has been adopted by Norfolk Children's Service and is a helpful way of implementing the conceptual framework of 'Think Family' in practice. In addition, it offers an opportunity to celebrate the importance of 'the ordinary' in the lives of adolescents by recognising their resilience and routinely identifying sources of safety, strength, risk, and vulnerability.

The Early Help Service provided a long period of support to the family. The work of 'Early Help' Services across the country have changed considerably over recent years. Currently, these teams routinely provide services to families who are regarded as having complex needs that sit just below the threshold of statutory child protection intervention (provided by Children's Social Care). As a result, Early Help Services provide services to families at one of the highest thresholds of statutory safeguarding intervention and, where needed, are well placed to take on the role of lead professional. However, this did not happen. It seemed that the potential benefits of their involvement was not understood by the multi-agency network and there appeared to be a misunderstanding about the principles underpinning their approach.

At best, it seemed that the Family Support Plans drawn up by the Early Help Service were not regarded as carrying as much weight as other agency/service plans and at worst the approach was regarded as ineffective and 'collusive'. In addition, there appeared to be a reluctance by Early Help to fully step into the role of lead professional. The reasons for this are unclear but it seems reasonable to suggest that these difficult professional relationships would have been a complicating factor. As a result, the potential benefits of providing a lead professional and an integrated

³⁶ The Family Support Process (FSP) Handbook for Professionals <https://www.norfolk.gov.uk/children-and-families/early-help-and-family-support>

³⁷ This strengths-based and safety-focused approach is grounded in partnership and collaboration. It expands the investigation of risk to encompass strengths and Signs of Safety that can be built upon to stabilise and strengthen a child's and family's situation.

multi-agency response was not realised. This had a significant impact on how the needs within the family were understood and had a detrimental impact on service provision.

ii. Family Therapy

One of Child AE's consistently expressed wishes was for his family to receive family therapy. When family therapy was provided, Child AE reported helpful changes in family relationships. These changes were important to Child AE and his brother.

Family therapy is provided within Tier 3 and Tier 4 CAMHS. The value of family therapy is extensively recognised as improving outcomes for children and is a therapeutic service that epitomises the principles of a 'Think Family' approach. It was acknowledged by family members and professionals alike that family life could be difficult, and family therapy was an important component of Child AE's care plan. However, family therapy was only provided on 2 occasions.

The report author was told that the reason for this was partly because of the instability of Child AE's mental and physical health but also because of difficulties in completing the work in a constructive way. The report author found evidence in case records of one occasion when a family therapy session was clearly difficult for all. After this session, no further family therapy sessions were offered either by the Tier 4 Unit or by community services.

Providing services to children and families involves an imbalance of power between professionals and families and can involve contending with difficult relationships. Families can feel judged and intimidated by professionals and professionals can also feel intimidated and be at the receiving end of hostility. During a recent SCR in Norfolk³⁸ focus groups were held with front line practitioners to learn from their experiences of working with families when they experience hostility. The report makes the following comment: *It was recognised that this can feel traumatic and stimulate feelings of threat/danger which raises anxiety, inhibits curiosity, and can stimulate a fight/flight/freeze response. In the absence of sufficiently containing supervision/support from their organisation, this can remain unchecked and have a long-term impact on their work.*

Supporting Families : Conclusion and Recommendations

Think Family: Changes in Early Help Services over recent years have been considerable. Early Help provides a non-stigmatizing service to children and families and occupy a pivotal place within the safeguarding landscape. However, the benefits to children and families, and multi-agency partnership working, have not been fully understood or realised.

³⁸ Norfolk Safeguarding Children Board Thematic Serious Case Review. 2019

Recommendation 8: Norfolk County Council Early Help Service to work in collaboration with front line clinicians, practitioners, managers and senior partners to understand the difficulties in achieving an integrated multi-agency response to vulnerable children (whose needs sit under the threshold of Children’s Social Care) and take remedial steps.

NSCP to be informed of progress and provide support and challenge.

Family Therapy: It is without doubt that staff require the support and protection of their organisations in order to work in the challenging arena of childcare, therapy, treatment, and child protection. It is equally accepted that it can be difficult to engage families in therapy as there will often be resistance to changing established patterns and familiar dynamics. Accountability is held by both professionals and parents alike to constructively engage in this therapy. The challenge presented is that if family therapy is regarded as a critical part of a child’s treatment plan, but does not happen, how will the multi-agency network work together to galvanise their collective skills and find creative ways to work with the family to meet their needs?

Recommendation 9. Norfolk and Suffolk NHS Foundation Trust & Norfolk Children’s Service to collaborate in an attempt to find creative and flexible ways to engage families in family therapy. Services to consider what more may be needed to support practitioners/clinicians in this work.

NSCP to be informed of progress and provide support and challenge.

5. Dealing with complaints & responding to anxiety

The multi-agency involvement in this case was marked by some exceedingly difficult relationships between professionals and with Child AE’s parents. It was clear that there was a great deal of energy, time, and resources, invested by his parents and by professionals and managers when responding to requests, concerns and demands.

The demands on all family members when caring for a child with complex physical and emotional needs are vast, and there is understandable anxiety about the child’s wellbeing. The absence of a school place and the lack of a holistic approach across the agencies (resulting in the multiple professionals, care pathways and processes) had the unintended consequence of compounding the isolation felt by Child AE and his family, and contributed to the significant physical, financial and emotional pressures and feelings of anxiety. In addition, when services did not sufficiently respect Child AE’s parents as equal partners, and did not place the family at the centre of their interventions, this led to an escalation of anxiety and feelings of

powerlessness which served to increase the intensity of the conflict and led to an escalation of complaints.

During the period under review, Child AE's parents made 30 formal complaints to various agencies and raised concerns with their MP, senior leaders, and a number of regulatory and government bodies. The central driver behind these complaints was a wish to achieve the best possible service for Child AE. However, the unintended consequence was that professionals and services became increasingly defensive, prescriptive, and procedurally bound.

Professionals spoke about feeling intimidated and disempowered by the volume of complaints and the involvement of senior managers and MP's. This undermined staff confidence, diverted attention away from meeting Child AE's needs, compounded the isolation felt by Child AE, added to the splits in the network and led to feelings of anxiety, frustration, sadness, and anger. A significant amount of extra work was created, communication channels were confused and on occasions this led to fault finding/looking for blame within the professional network.

In this working environment, the more complaints were made (and left unresolved)³⁹ the more defences were erected, the more the conflict rose, and the more splitting and fragmentation of services emerged - someone was to blame. In this turbulent environment, the focus on Child AE was lost. There was little containment for Child AE, for the family, for the professionals and the system. Conflict and disagreement continued, and the lack of containment echoed across the network and persisted throughout - up to and including the final days of Child AE's life.

Learning from research and literature

Psychodynamic literature explores the human and organisational response to the emotional content, and the inherent anxiety, of working with children and families and suggests that in the face of this anxiety individual and organisational defences are constructed. A variety of authors⁴⁰ have discussed the impact on a range of sectors, arguing that these defences can have a significant impact on the culture of an organisation and how the organisation, and individuals within it, perform the tasks of the organisation internally and collectively across the multi-agency system.

In addition, the work by Research in Practice⁴¹ and Dr K Triesman⁴² has encouraged organisations to pay attention to the significant emotional challenges faced by professionals when working with children and families; the secondary trauma that can be experienced and the defences that can be constructed which have an important impact on the services provided.

³⁹ Of the 30 formal complaints made, Child AE's parents received only 1 formal response

⁴⁰ Such as : Eds: Obholzer and Roberts (1994, 2019), Armstrong and Rustin (2015), Hoggett (2010) Pengelly and Woodhouse (1991)

⁴¹ Developing and Leading trauma informed practice. Research in Practice Dartington 2018

⁴² Safe Hands Thinking Minds Dr K Triesman <http://www.safehandsthinkingminds.co.uk/>

We are all susceptible to taking a defensive position and these defences are wide ranging. Each of us construct our own narrative to explain events. Typically this is accompanied by an inability to hear other narratives or entertain the idea that all are constructions rather than facts, and none are right or complete. Serious Case Reviews have identified the impact of these defences. Those relevant, but not exclusive to this SCR, include:

- A reduction in critical thinking
- Tunnel vision
- Attempts to find blame
- Defensive practice
- Overly strict rule/procedural compliance
- Relationships characterised by conflict & splitting
- Reduced ability to see the child & the whole picture
- Reduced ability to listen
- Isolated working – reducing collaboration

What did Child AE, family members and professionals need ?

i. Leadership

In the midst of this was Child AE and his brother. Whilst CAMHS were mindful of the impact of serial complaints, it was difficult to see what was done across the multi-agency group to fully stand in the children's shoes and understand their experiences of this conflict between those responsible for their care. A recent SCR in Norfolk has identified this as important learning.⁴³

During this SCR, the Lead Reviewer found that the majority of clinicians/professionals felt they would not be sufficiently supported by their organisations to be assertive and make decisions with confidence that placed Child AE at the centre, as a result decisions were tempered by concerns about parental response. Some spoke about a lack of senior management support to resolve difficulties and some spoke about a management response that undermined their decision making and work.

It is of note that during the meeting with Child AE's parents, as part of this SCR, they spoke about wanting *someone to take accountability*: to make difficult decisions, to be accountable for these decisions and on occasions to say 'No'. As stated, this may have only been clear with the benefit of hindsight. That said, there was a need for accountability to be strengthened and this applied to parents and professionals alike.⁴⁴

⁴³ NSCB SCR Case U 2018

⁴⁴ For example: the responsibility to engage in family therapy, and so meet Child AE's wishes and needs, was a requirement for parents and professionals and the impact of multiple complaints and conflict on Child AE was also a mutual responsibility

Overall, it seemed that the very thing wanted by both professionals and parents was strong clear leadership that featured a willingness to have courageous conversations with parents and practitioners, to challenge, to hold accountability for decision making and thereby provide containment for the whole system (professionals, parents and children).

ii. Supervision

Reflective supervision can provide a vehicle to support the emotional wellbeing of staff by offering a containing space that can soothe anxieties and enable the totality of child and family life (and service response) to be thought about. Whilst professionals spoke about receiving supervision (and there was evidence of group supervision in CAMHS), this supervision was single agency and therefore potentially added to the proliferation of single agency tasks and fragmentation.

There was a desire to hold multi-agency meetings without the parents being present and this may have been an attempt to achieve a unified approach. However, there was resistance to this concept by parents and professionals alike. Positions were taken (supported by relevant guidance, established practice, and procedure) that it was not appropriate to hold meetings without parental presence.

Relevant guidance and procedure correctly states that services should always attempt to work in full partnership with parents. However, interpreting this to mean that a multi-agency group can never meet without parental presence is an overly rigid interpretation of this guidance. Supervision is a necessary tenet of professional development that seeks to support staff and improve service provision, for obvious reasons this is always carried out without parental presence. In circumstances where there is wide ranging involvement from multi-agency professionals and services, there is a clear need for multi-agency intervention to be supported by group supervision.

iii. A 'just learning culture'

There is a significant body of research and literature⁴⁵ that examines how organisations create an optimum culture to create safety and improve service delivery. At its core is the recognition that 'just learning cultures' need to be in place where there is space and permission to say: 'this is not working – we need help', for human error to be recognised and accepted (without punitive repercussions) and used to better identify organisational learning. In organisational cultures and multi-agency systems where it is not permissible to say no, to be uncertain, not to know or

⁴⁵ Such as: The Munro Review of Child Protection: a child - centred system. Professor E. Munro. UK Gov 2011. Behind Human Error. Woods Dekker et al 2010. The Field Guide to understanding Human Error S. Dekker. 2014.

to make a mistake, defences are constructed which ultimately have a detrimental impact on the services provided to children and families.

Dealing with complaints and responding to anxiety: Conclusion and Recommendations

Dealing with complaints. The multi-agency system is imperfect, there is a need to recognise this and the impact of multiple complaints on children, families, staff and on the system. Recognising impact and responding to complaints in a fair, accountable and proportionate, manner is not mutually exclusive. Strong leadership is needed that features clear lines of accountability/responsibility and containment for children, parents, and staff.

Recommendation 10. NSCP to bring together senior leaders from across the multi-agency partnership to agree a multi-agency strategy to deal with multiple complaints. Components of this strategy should include the need to minimise collateral damage to the child and family and the multi-agency front line, the requirement to have courageous conversations and hold a senior line of accountability. In exceptional cases, external consultation should be commissioned to provide support.

Supervision. Good quality, reflective, supervision can provide a space where; the totality may be seen, anxiety contained, defences understood, thinking expanded, and collective responsibility held. In order for clinicians and professionals to provide the best possible service to children and families, good quality multi-agency supervision is needed.

NSCP have recently piloted a multi-agency supervision forum and the feedback has been positive. The questions that arise in this case are whether any of the professionals who could have referred would have identified this as a challenging and complex case and whether, given the very significant number of clinicians in this case, an alternative health based model such as Schwartz rounds⁴⁶ (currently taking place in NHS trusts across the UK) may have been an appropriate, and acceptable, approach in this case.

Recommendation 11. NSCP to evaluate the recent multi-agency joint supervision pilot and provide a multi-agency supervision forum for front line staff that is consistently available, sufficiently promoted, and independently facilitated.

Recommendation 12. Norfolk Community Health & Care NHS Trust and Norfolk and Suffolk NHS Foundation Trust to consider what is needed to promote an integrated service response to complex clinical presentations. Any approach

⁴⁶ <https://www.pointofcarefoundation.org.uk/our-work/schwartz-rounds/about-schwartz-rounds/>.

should include reflective supervision and be consistent with the Royal College of Paediatrics and Child Health (RCPCH) guidelines.

NSCP to be informed of progress and provide challenge.

‘Just learning’ cultures: The work of organisations tasked with the care of children is fundamentally a human system and the emotional experience of individuals, organisations and systems are an important feature of how the quality of services are achieved. In a working environment that is fraught with anxiety and where little containment can be found, the universal human response to this anxiety (of fight, flight, or freeze) makes it impossible for a coherent professional response to be provided. Changing the learning cultures of organisations will not be achieved by a single recommendation, it requires a long-term plan to determine how this will be promoted.

The introduction of Schwartz rounds is a testament to how the benefits of a ‘just learning culture’ has been recognised by some NHS trusts.⁴⁷ Norfolk recently published a Thematic Review⁴⁸ where the impact of individual and collective defences has been identified and recommendations have been made. This SCR has been accepted by NSCP, including the principle that a just learning culture needs to be promoted, the recommendations set out in this report are relevant to this SCR. As a result, no further recommendations are made.

End Notes

- i. **Educational SEN & Disability Tribunal, the Root Cause Analysis Investigation, LADO involvement and Inquest.**

This SCR has referenced these processes which have explored specific areas of service provision to Child AE, and his family, in considerable detail. It has been stated that this SCR will not repeat the learning that has already taken place. However, during the final stages of this review the report author learnt that Child AE’s parents had not been informed, as they should have been, about what actions have been taken by the responsible agencies and services in response to, in particular, the orders made by the District Judge and the relevant conclusions of the Coroner. Attempts were made by Norfolk Safeguarding Children Partnership to gain clarification but at the time of writing this has only been partially resolved. A number of these recommendations/orders/findings were of a profoundly serious nature and have a significant impact on how children in Norfolk are safeguarded and their needs met.

⁴⁷ NHS A just culture guide 2018 <https://improvement.nhs.uk/resources/just-culture-guide/>

⁴⁸

Recommendation 13. NSCP to seek assurances that the findings/recommendations and orders of the relevant processes have been actioned and Child AE's parents informed.

ii. Involving Family Members in SCRs

As noted earlier in this report, a meeting took place between the Lead Reviewer and Child AE's parents at the start of this SCR. Once the report had been finalised, a meeting was held between the Author, the Chair of the Serious Case Review Subgroup and Child AE's parents. A subsequent meeting took place involving Child AE's parents and the Chair of NSCP, and further meetings between the Author and Child AE's parents followed. What became evident in the course of these meetings was that the traditional ways of involving parents in SCRs (often only at the beginning and the end of SCRs) should be reviewed. If we are to fully stand in the shoes of families and understand their experience of service provision, parents should be offered the opportunity to be an ongoing part of the SCR process and fully involved throughout. This includes placing the same value on the documents/evidence families may hold about service intervention as those documents produced by agencies as part of a SCR.

Grateful thanks are extended to Child AE's parents' for the patience and time they have committed to this review.

Recommendation 14: NSCP to embed this learning into current SCR/CSPR processes to establish a mechanism that will allow families to fully participate.

Conclusion

At the close of this SCR it is important to return to Child AE. This review has shown that despite the commitment of many involved in his care, it was not possible for his wishes to be fully honoured or his needs fully met. At the heart of the difficulties was a system of professionals and parents that was fragmented. Sadly, this fragmented system is not unique to this case nor is it unique to Norfolk. Child AE's experiences starkly illustrate that when responding to children's unique needs, the system responds by splitting the child's needs into parts where answers are sought, and multiple answers are provided (all partly right but totally unintegrated). This leaves the child being defined by a collection of illnesses/conditions/service challenges and responses.

It is perhaps unsurprising that the vast majority of SCRs identify problems in information sharing, joint working, and collaboration. Making recommendations that view the multi-agency children's workforce as a united service, and expecting them to respond as if they are, is simply unrealistic.

Within this landscape are multiple front-line practitioners and clinicians, working with vulnerable children and families, who are attempting to navigate the complexity of

the system. In this imperfect system it seems inevitable that when faced with a child in need who may be in pain and distress, where little can be done to make a discernible difference to their life, anxiety will be present, and emotions will emerge. For the front line this can lead to defences being constructed to cope with this anxiety, and for parents this can lead to battling with professionals and the system. If uncontained, this emotional response will further destabilise the system and the child may be lost.

This SCR urges leaders to acknowledge the shortcomings in the system and that there are no easy answers, or quick fixes, to deal with the complexity. Instead, this SCR asserts there is a need to respond to the human condition and place some basic principles at the heart of the system. Put simply, this includes; supporting staff to navigate the complexities of the fragmented multi-agency system and to find opportunities to bridge the gaps between them; authorise and embed multi-agency supervision so that it becomes an essential component of multi-agency work; value the importance of ordinary life for children and families; and achieve a close partnership of mutual care and accountability between professionals, agencies and parents.