Child Safeguarding Practice Review

Stephen Wilson

June 2022

This is not the right place - A System in Crisis?

I could not believe that this could happen in this country in the 21st century …. People normalise and collude because they are working in a fallible system that is not fit for purpose.

(Stephen's mum)

Executive Summary

This CSPR is about the multi-agency services provided to Stephen and his family. Stephen is currently living in a mental health inpatient unit. He is the only patient in this unit. Stephen is restrained daily in order to be fed and to receive medication and personal care. Stephen has not spoken for over 12 months and his interaction with the external world is minimal.

Stephen has been an inpatient in different mental health units since his early adolescence. This CSPR commenced after Stephen was admitted to an acute hospital from one of these inpatient mental health units. Significant concerns about his wellbeing as a result of the care he had been receiving were identified. The focus of this CSPR has been on the circumstances surrounding this incident and wider systemic issues influencing the care and support provided to Stephen and his family from an early age. The wider systemic issues identified at the Rapid Review included concerns about the availability and suitability of inpatient mental health beds for children particularly for children whose needs are complex.

Mental health inpatient care is by no means a panacea, research is clear that it should not be regarded as a cure and for many children, particularly for children with an ASD diagnosis, everything possible should be done to avoid admission. This CSPR has identified that whilst the lack of availability and suitability of inpatient beds is a clear issue affecting the care and treatment of children, there are wider systemic issues that also require attention particularly in relation to how services work together to prevent difficulties escalating. These issues include the need for early assessment and service provision to children where there are concerns about possible autism, careful planning of a child's transition from primary to secondary school, the importance of an early Education and Health Care Plan Assessment and the need for joint multi-agency collaboration to find creative solutions to support children and families in the community.

Many of the issues identified in this CSPR are not new, many are national issues effecting a wide group of children. Since this time, multi-agency services have evolved and strengthened in some key areas that may have made a difference to Stephen and his family. This CSPR has identified that there is still more to be done if we are to safeguard children such as Stephen and provide children and their families with the help they need at an early point.

It is important to recognise that during the key period under review the Coronavirus Pandemic was an important systems dynamic that had multiple consequences across the entire multi- agency system. That said, there were other factors that influenced the services that were provided - these factors are set out in this CSPR.

Finally, throughout this CSPR it has been clear that the workforce proving care to children such as Stephen is a compassionate work force often doing the best they can. However, in a fallible system compassion fatigue may set in and this requires attention by organisations tasked with providing human services.

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Reason for this CSPR

Stephen was admitted to hospital when he was 15 years of age from an inpatient adolescent mental health unit. On admission to hospital, staff expressed concerns about his physical and emotional health. Stephen appeared emaciated and dehydrated. His underwear was soiled and soaked though to his jeans, his buttocks were red, his clothes were dirty, his feet were red and sore, he was distressed and afraid to return to the inpatient unit. There were significant concerns that Stephen had suffered neglect and emotional harm whilst at the inpatient mental health unit. A Local Authority Designated Officer (LADO) and a criminal investigation commenced; the conclusion of these investigations was that Stephen's welfare had been put at risk of significant harm due to *institutional processes.*

The Coventry Safeguarding Children's Partnership (CSCP) reviewed Stephen's experiences in June 2021 and concluded that the criteria for a Child Safeguarding Practice Review (CSPR) had been met. The Rapid Review[1] (RR) identified various concerns particularly in relation to the lack of inpatient beds for children and adolescents suffering a mental health crisis. The National Panel were informed of the decision to commence a CSPR and was asked to consider a national review of this issue. The view of the National Panel was that Stephen's experiences raised a potential issue of national importance relating to the mental health of young people and the support provided to them and suggested that they may wish to draw on the learning in this CSPR in any potential future review.

Purpose and Methodology

The purpose of a CSPR is to learn lessons through a systems analysis of the single and multi-agency work and provide a proportionate and meaningful account of what happened from the perspective of the child and family. The methodology used in this CSPR endeavours to understand professional practice in context, identifying systemic factors that influence the nature and quality of work with families.

Process of review

A key aspect of the approach is for an independent reviewer to work with a review team to plan and organise the key tasks, participate in the meetings, read key documents, and analyse the data in order to produce the findings. In this case an experienced independent reviewer, Bridget Griffin[2], worked alongside the panel chair,[3] and senior panel members representing multi-agency services in the local area.

Involvement of families & practitioners

Stephen's mother (Ms Wilson) has been involved throughout this CSPR. Stephen's father was invited to participate in this CSPR but decided not to be involved - the view of parents is that Ms Wilson is well able to represent parental views. Parents work closely together to advocate for Stephen in his current circumstances. It has been, and continues to be, an extremely difficult time for Stephen's parents in circumstances where their son continues to suffer from significant mental ill health, where there are no clear plans about Stephen's future care and no guarantee about recovery . Grateful thanks are extended

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[1] A Rapid Review is a multiagency review of a case that is carried out in response to a serious child safeguarding incident. A RR must take place within 15 days of a serious incident notification. The purpose is to gather the facts, identify immediate learning and decide whether the case meets the criteria for a CSPR.

[2] CQSW, BA (Hons), MA (Tavistock & Portman and MHT), SCIE accredited reviewer.

[3] Consultant Paediatrician and Designated Doctor for Safeguarding Coventry and Warwickshire Partnership Trust

to Ms Wilson for her involvement in this process. It has not been possible to speak to Stephen about this review. During his illness he became mute and remains so; he has little engagement with the external world. It was felt that to try and engage Stephen in this CSPR would be detrimental to his wellbeing - his current treatment and wellbeing is of utmost priority.

Conversations were held with key practitioners and a learning event was held with practitioners who had worked with Stephen. This event included practitioners who are currently involved in his care. The perspective of these practitioners are reflected in this CSPR.

Timeline

The timeline under review was originally set between January 2020 to December 2021. However, as more information became available, it was felt important to extend the timeline to include as much as possible about Stephen's early years in order to try and understand what might be needed to prevent children from suffering the same experiences as Stephen .

Stephen Today

Stephen is 16 years old; he has been living in a local inpatient unit for over 12 months. He is currently living in an annex to the main hospital and is the only person living here. The furnishings in his accommodation are bare as there is a need to deep clean his room regularly. Stephen receives intensive care from a team of staff and has been under constant clinical observation throughout the unit.

Twice a day a team of five staff, who are specialists in restraint, enter the unit dressed in hazmat suits. Stephen is fully restrained and receives liquid food and medication through a naso gastric tube and is washed and changed. The process lasts approximately 20 – 30 mins. For the rest of the day Stephen sits on the floor in a crouched position, he is mute and has not engaged with any activities or with staff until very recently when there have been some small but hopeful signs that Stephen is starting to make a connection with staff and his environment.

Stephen's history and involvement of agencies.

Early history: Stephen was a child who liked school and had close friendships. During infancy and early childhood, there were no behavioural difficulties or concerns about his emotional wellbeing at home or school. At 8 years, in year 4 at primary school, it was noticed that Stephen was experiencing heightened levels of anxiety. Ms Wilson was concerned about his anxiety, she said this was more apparent at school. In Year 5, teaching staff were concerned about his increasing anxiety and questioned whether Stephen may have Autistic Spectrum Disorder[4] (ASD). A referral was made to the Child and Adolescent Mental Health Service (CAMHS).

Stephen was 10 when he was seen at CAMHS for an initial appointment. He was referred to the Neuro Developmental Team (NDT) for an ASD assessment and to a 'Young Minds' project to help with his anxiety, which he attended for six weeks. Ms Wilson said she was told by CAMHS – *we do not see children with autism*. It is understood that CAMHS may not need to be involved with children who have an autistic

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[4] The Autistic Society now advocate using the term Autistic Spectrum Condition.

spectrum disorder (ASD). There are many children with an ASD who do not need CAMHS services, and it was expected practice to refer a child with anxiety to third sector organisations such as Young Minds.

Ms Wilson was concerned about how Stephen was managing transition from home to school and his return to school after a break. At home, Stephen started to hoard. He would smash things and was significantly anxious if his possessions were touched. He was not coping well with peer relationships and needed a lot of reassurance. The view of Ms Wilson was that possible difficulties in transition to secondary school were not adequately predicted by the primary school.

During this time, Stephen's parents separated. Ms Wilson describes this as a very difficult time for Stephen which was compounded by his move to secondary school in September. The secondary school provided support to Stephen before and during his transition. Ms Wilson described the routine and sensory overload at secondary school as being *overwhelming* for Stephen although she said he found the structure of school and being part of a school community beneficial.

Practice Learning: The importance of transition

The work of the secondary school in supporting Stephen's transition was good practice. Whilst Stephen was in primary school, a member of staff from the secondary school visited Stephen and Stephen visited the secondary school. Ms Wilson and father accompanied Stephen on his first day and stayed whilst Stephen attended his first lesson. Although he found it difficult to separate from his parents - during the day he settled well and was observed to be smiling and engaging well. There was daily contact between staff and parents during Stephen's attendance at the school – Stephen was a quiet nervous child who needed support throughout. He was placed in a nurture group and gradually transitioned into mainstream school life and saw a school councillor on several occasions. School provided creative and consistent support to respond to Stephen's various needs and enable him to remain in school at this time.

An ASD assessment was completed in May 2018 (3 years after referral had been made), Stephen was 12. It is understood that it is not unusual for there to be such a long wait for an assessment in the local area, and this is attributable to the high demands and limited capacity of this service. This is reflected nationally. The question that arises is whether the long wait for an assessment and diagnosis impacted on Stephen. The view of Ms Wilson is that this long wait was unhelpful as it meant it was difficult to fully understand his needs and make the adjustments that were needed at home and school over these years. She described this period as a very difficult time; his parents had recently separated which contributed to an increase in Stephen's anxiety and Stephen's behaviour was impacting on family relationships and dynamics. She struggled to understand what she could do to help. She observed Stephen to be in emotional pain and struggling with high levels of anxiety but felt at a loss to navigate her way through life as a mother of two boys in a stressful home environment*: 'I felt under terrible strain and was increasingly anxious.'*

The assessment completed by the NDT confirmed a diagnosis of ASD and Ms Wilson was advised to seek an Education and Health Care Plan (EHCP). The assessment was shared with the school but there was no liaison with the school from this service or from CAMHS. It is understood that NDT is purely a diagnostic service, it is not resourced to provide ongoing input post diagnosis. In addition, there was no established link between the school and CAMHS. Since this time, the Complex Communication Team and The Mental

Health Support Teams in schools[5] have become established and it is understood that these teams would now provide support to children and families when a child has received a diagnosis of ASD.

August 2018. Stephen 13 years: Ms Wilson school referred to CAMHS as there were concerns about Stephen's increasing levels of anxiety. An assessment at CAMHS led to a recommendation that Stephen should attended an ASD anxiety group, and that a referral would be made. Ms Wilson said this did not happen and the records do not evidence that this referral was made. The reason for this is not known. There was no ongoing work by CAMHS at this time with Stephen or with the school. CAMHS recommended that an EHCP should be pursued.

Practice Learning. EHCPs: The NDT and CAMHS advised Ms Wilson to request an Education, Health Care Plan Assessment (EHCPA)[6] – this was appropriate advice as it was important to ensure a statutory framework was in place to meet Stephen's additional needs in school over time. It was understood from Ms Wilson that the school declined to pursue this as it was felt Stephen's needs were not significant enough. The position of the school was that there was little more that could have been put in place to support Stephen at school and that an EHCP would not have made a difference to the support that was in place. Whilst this may well have been well intentioned, the importance of EHCPs should not be underestimated for children with ASD/mental health needs and it is important to note that the agencies involved had a responsibility to make a direct request to the Local Authority for an EHCPA. Whilst at the time it may have appeared that the school could meet Stephen's needs, and little more could have been done by the school to support him, there was a measure of optimism that may have been warranted at the time but over time proved to be misplaced.

In January 2019 Stephen attended regular appointments at CAMHS. There was no joint working between school and CAMHS during this time (Ms Wilson described herself as *the go between)*, and there was no referral to Children's Services (CS) by the practitioners involved.

Practice Learning. Multi-agency working: Whilst Ms Wilson says she did not support a referral to CS at the time (as she was unclear about what would be provided that would help) this needed to be explored with Ms Wilson and with CS. It is understood that if consent had been gained and a referral had been made, an assessment would have been completed either by early help or CS to explore the support Stephen and his family may have needed. This could have included access to short breaks, which could have provided respite for Stephen and his family and could have supported Stephen to engage in community activities. In addition, a lead practitioner would have been available to support coordination of the overall plan for Stephen (either a Child in Need plan or an Early Help plan), this would have brought the network together for regular reviews of Stephen's needs and of the plans to meet these needs. In the absence of a lead practitioner, there is a risk that the service response to children and families is fragmented. This is discussed in the key findings.

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[5] The Mental Health Support Teams in schools were established in the local area in Jan 2020. However, not all schools are engaged with the project.

[6] An education, health and care plan (EHCP) is for children and young people aged up to 25 who need more support than is available through special educational needs support. EHCPs identify educational, health and social needs and set out the additional support to meet those needs. An EHCP commences with a EHCP assessment (EHCPA) and takes up to 20 weeks from initiation to finalisation of assessment and decision.

The start of school year in September 2019 was difficult for Stephen (aged 14 years.). Stephen started to struggle with his eating. Ms Wilson felt that his eating difficulties were linked to changes that occurred in school and said the school were supportive.

In October 2019, Stephen was seen for a psychiatric review and a referral was made to the CAMHS Eating Disorders Team (EDT) for an assessment. An appointment was offered but Stephen declined to attend the appointment. Based on the information shared with this team, the view was that Stephen did not meet the criteria for the service as he was not presenting with a typical eating disorder. Rather, he was presenting with Avoidant/Restrictive Food Intake Disorder (ARFID). It is understood that many children with ASD have issues with food, textures, and tastes but that this does not constitute an eating disorder (ED) and the EDT would not meet their needs. However, EDT remained involved by providing support to CAMHS.

In November, CAMHS shared concerns with school about Stephen's loss of weight and that this seemed to be linked to anxieties surrounding school. It was agreed that the need for an EHCPA would be discussed within the school with a subsequent decision that the school would pursue this. However, it is understood that agency can request an EHCPA, and this should have been pursued by CAMHS. An EHCP was not put in place until 2021.

December 2019 – January 2020: Stephen 14 years. Stephen started to see a counsellor in CAMHS in December and this continued until June. Stephen attended every session, a total of 16 sessions in all. Escalating concerns about Stephen's anxiety, loss of weight and fainting at school led to him attending part time education. Whilst it is understood that this decision was made with the best of intentions, this represented a loss of structure and routine at this time which Stephen found difficult. Over the following weeks, there was a rapid deterioration in his mental health and wellbeing, and by mid-February 2020 he was out of school altogether.

Whilst there was some communication between CAMHS and the school, it seems that the first meeting that brought the school and CAMHS together was a Care Education and Treatment Review (CETR)[7] meeting in February. CETR guidance states that CS should be present at these meetings in recognition of the importance of multi-agency work, but no referral had been made to CS. This was at a time when the concerns about Stephen were considerable. It is understood that the school were contacted on 3 occasions by the CAMHS counsellor to discuss strategies of managing Stephen's anxiety in school and that school staff were able to contact CAMHS when needed. Whilst this is appreciated, it does not represent the kind of close joint working needed in these circumstances. It is understood that the recently established Mental Health in Schools Team has strengthened communication and dialogue between CAMHS and schools - this is an important development.

Stephen continued to be on roll at the school and study materials were sent to Stephen. Ms Wilson said that at this time he was unable to concentrate, and the focus was on trying to increase his weight. Stephen was becoming increasingly uncooperative at home; this was a change in his behaviour. CAMHS continued

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[7] A Care, Education & Treatment Review (CETR) is a meeting about a child or young person who has a learning disability and/or autism and who is either at-risk of being admitted to, or is currently detained in, an in-patient (psychiatric) service. CETR's recognise the significant role that education plays in children and young people's lives. Representatives from health, education and social care should all attend the meeting.

to remain involved - there were significant concerns about Stephen's loss of weight. He was weighed weekly.

March 2020: Stephen 14 years Ms Wilson reported to CAMHS that although Stephen was managing to eat some food, and on occasions attending to his personal care, he was not eating or drinking well and was refusing medication. She was advised to take Stephen to hospital where he was admitted due to low weight, low blood sugar, concerns regarding poor eating/drinking, anxiety and increasing ritualistic behaviour**.** Ms Wilson stayed on the ward with Stephen to assist in his care. She felt he was deteriorating in hospital and suggested he should return home.

A referral was made for inpatient admission to a general adolescent psychiatric unit. At the time there were several children waiting for an inpatient bed in the local area. There was a particular shortage of mental health inpatient beds at this time. Stephen's needs were regarded as complex and this, together with the impact of the coronavirus pandemic, added further layers of complexity in locating a bed.

Ongoing concerns about Stephen's eating led to consideration of nasogastric feeding (NGF). This required Stephen's consent which he refused. Consideration was given to assessing Stephen under the Mental Health Act (MHA) to enable this to provided and to Stephen's admission to an eating disorder inpatient unit. It was concluded that Stephen had an eating disorder, and this was regarded as the central concern. A bed was subsequently found in an inpatient unit. In the meantime, Stephen returned home to await admission. Whilst at home, Ms Wilson reported that things had improved; with her support, Stephen was managing to eat, attending to self-care, and communicating with her. She decided not to take Stephen to the inpatient unit in part because of the restrictions on her contact with Stephen due to the pandemic, and in part because her fears of Stephen catching coronavirus.

Over the following weeks, there was regular contact between Ms Wilson and CAMHS. Ms Wilson reported that although his eating remained concerning, he had gained weight and was showering weekly. She was worried about his ritualistic behaviours and anger outbursts, although was concerned that admission to an inpatient unit would lead to a deterioration.

Practice Learning : Inpatient care is not a panacea. Ms Wilson was right to be concerned about Stephen's admission to an inpatient unit. Research suggests that admission particularly over prolonged periods can be unhelpful for children especially for children with an ASD diagnosis. In the absence of alternative wrap around support in the community there is a risk that the default position can be inpatient care despite the research that suggests children with an ASD require the least restrictive setting, and that inpatient care may lead to further deterioration. It is understood that this gap in service provision for children with an ASD and complex care needs in the community is a national issue – this is discussed in the key findings.

During the next few weeks, Stephen's eating was minimal and increased ritualistic behaviour emerged. The view of CAMHS was that admission to an eating disorder inpatient unit was needed. A referral to Children's Services (CS) was discussed with Ms Wilson who said she was unclear about their input and did not want this referral to be made. Whilst consent for a referral to CS was needed, the importance of multi-agency involvement to safeguard children needed to be better understood and concerted efforts made by the services involved to gain consent for CS involvement. There was no involvement by the Transforming Care Team at this time, this is discussed in the key findings.

Stephen's rituals became increasingly elaborate, his self-care declined, his eating was minimal and there were continued concerns about his mental health. Apart from the CAMHS clinician, who had regular phone/virtual contact, no other services were involved. At the time, the country was in lockdown, and this may provide a partial reason for this. However, most importantly, it seems that there was little in place to provide intense support to young people and families in these circumstances. Whilst a referral to the Transforming Care Team had now been made, this was a recent referral. Discussions with Ms Wilson and practitioners, and a review of agency reports, suggests there is a lack of clarity about what this team could have provided either at this time or at an earlier point. This is discussed in the key findings.

June 2020: Stephen 14 years. Stephen was admitted to an inpatient unit (1) under Section 2 MHA[8] which was subsequently changed to Section 3 MHA[9]. During his stay, Stephen was experiencing severe anxiety and was frequently restrained as a result of various behaviours that were assessed as posing a danger to himself or others. Adaptions were made in the unit which Ms Wilson said seemed to work – '*they managed to establish a routine and stepped in quickly to proactively intervene.'* Ms Wilson felt Stephen '*did reasonably well'* at the unit. She said she had a good relationship with staff at the inpatient unit and was fully involved throughout Stephen's stay, although felt he was discharged too early. Records indicate that the plans had been to work towards discharge over a 6- 8-week period. It was understood that the restrictions in place linked to the pandemic/impending second national lockdown impacted on this discharge. It was felt that Stephen would not cope with the various transitions/not being able to see his mother over this period. As a result, the period of transition from the inpatient unit to home was reduced to a period of approximately three weeks. It has also been noted in agency records, and by Ms Wilson, that there was a view this unit was not the right place for Stephen due to the complexity of his needs relating to ASD and eating difficulties. Responding to complexity emerged as a systemic theme within this CSPR and is discussed later.

October 2020: Stephen 15 years. Stephen was discharged home on a Community Treatment Order (CTO)[10].

The discharge plan included a need for a referral to be made to CS and a request to school to refer Stephen for an Education Health Care Plan Assessment. These referrals should have been completed at the point of Stephen's admission. The Local Authority Children's Services have duties under Section 85[11] of the Children Act (1989) and under Section 117[12] of the Mental Health Act (1983) and discharge planning should commence at the point of a child's admission. The importance of making these referrals early did not appear to be understood. As a result, an EHCP was not progressed, and a referral was made to CS at

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[8] Section 2 of the Mental Health Act 1983 allows for compulsory admission for assessment or assessment followed by treatment in a hospital for a maximum of 28 days.

[9] Section 3 of the Mental Health Act 1983 is commonly known as "treatment order" it allows for the detention of the service user for treatment in the hospital based on certain criteria and conditions being met. These are that the person is suffering from mental disorder and that the mental disorder is of a nature or a degree which warrants their care and treatment in hospital and also that there is risk to their health, safety of the service user or risk to others. It also requires that the treatment cannot be given without the order being in place and that appropriate treatment must be available in the setting where it is applied. It lasts for a maximum of 6 months.

[10] A CTO is an order made by a responsible clinician under the Mental Health Act 1983 to provide supervised treatment in the community. This means treatment can be provided in the community instead of staying in hospital. A CTO allows recall to hospital for immediate treatment if necessary.

[11] Section 85 of the Children Act 1989 places a duty on local authorities to check on the safety and welfare of children living in residential education or hospital provision for any continuous period exceeding and/or likely to exceed 12 weeks.

[12] Section 117 of the Mental Health Act 1983 covers aftercare services which includes CSC, they are intended to meet a need that arises from or relates to a mental health problem and reduce the risk of readmission.

the point of discharge. The discharge plan stated that a referral to the community ED service was needed. This did not seem to happen. It is unclear why not; it may be that the original decision of this service that Stephen did not meet the criteria may have played a part in this lack of referral.

8/10/20 – 20/11/20: Stephen 15 years. During this period, Stephen lived at home with his mother. Support in the community involved a CAMHS care coordinator and psychiatrist, an Intensive Support Team (IST) and an occupational therapist. The hospital school provided 2 sessions of education a week and CS were involved. Ms Wilson described Stephen as having a full vocabulary, of managing to eat twice a day and showering once a week at this time.

20/11/20: Stephen 15 years. Stephen was admitted to an acute hospital after escalating concerns about increasing risk to himself including an overdose, an attempt to jump from a window and tying a ligature. After 2 days Stephen was deemed to be medically fit, and Ms Wilson agreed he should return home.

Two days later, police attended the family home after Stephen had attempted to jump from a window. The CTO was recalled, and Stephen was admitted to a local acute hospital paediatric ward due to escalating concerns about his eating difficulties and suicidal ideation. A referral for an inpatient bed was completed by CAMHS. It was later learnt that this referral was not explicit about his eating difficulties and the need to administer nasogastric feeds (this is discussed later), the primary concern highlighted was the risk of suicide.

Practice Learning. Providing care to children with mental ill health in general paediatric wards: Stephen's needs were at such a level that providing care and containment was extremely challenging in the paediatric ward. Whilst there was senior management input to try and resolve this issue, and Stephen was discussed in several escalation calls under the 'Child in Crisis protocol,' it was understood that at the time there were no inpatient mental health beds available locally or nationally – with 10 other patients waiting for a bed at this time. In addition, there is no urgent inpatient mental health provision available for children. It is understood that this is a national issue. Ward staff said they do not feel equipped to manage children with an acute mental health provision and there are concerns about the impact on other children on the ward. An additional issue raised by ward staff is that they do not have access to CAMHS records or to routine CAMHS support.

Whilst there was ongoing frequent involvement by CAMHS with Stephen, it is understood that CAMHS clinicians were not readily available to advise ward staff about care and treatment. This risks compromising an integrated informed care approach and did not provide the support to ward staff that is felt to be needed. In addition, the pressure on the availability of beds in child and adolescent inpatient units means that children may remain in unsuitable environments longer than needed. Given these national pressures, it is likely that this effects a significant group of children at any one time and is likely to remain an issue until addressed.

Since this time, daily multi-disciplinary meetings known as 'Bronze or Silver Meetings' take place to coordinate services as fully as possible to provide the most appropriate care in these circumstances and escalation to the commissioners of inpatient beds (NHS England) is discussed. In addition, a 'Think Family Outreach Team' has been established who support children on the ward – this has been positively received although there remains an outstanding issue about the appropriateness of the general paediatric ward environment for these children and the support provided to staff in these circumstances. This is discussed in the key findings.

The lead clinician initiating the recall of the CTO was not approved under Section 12 (MHA)[13]. This meant that Stephen was illegally detained in the general hospital and during his initial stay at the inpatient unit where he was later admitted. The inpatient unit promptly identified this matter and Stephen was assessed by an Approved Mental Health Practitioner (AMHP) from CAMHS when the CTO was legally revoked. CAMHS have identified that investigations have been completed and actions taken to address to prevent reoccurrence, it was not found to be a systemic issue.

Transfer to inpatient unit (2). Five days later[14], a bed became available at an independent sector inpatient unit and Stephen was quickly transferred that evening.

Practice Note: Transfer of care: It is accepted that there was a need to move Stephen to a more appropriate placement and, with the best intentions, it was believed that he needed to move quickly in order for his needs to be met. However, children need to be given time to prepare for change and Stephen's needs relating to his ASD needed to be considered and met in relation to how this move was managed. This hasty move impacted on Stephen's levels of distress– this represents a traumatic event for Stephen and Ms Wilson. It is understood that the challenges of meeting Stephen's needs and the scarcity of inpatient beds contributed to the decision to move Stephen as quickly as possible once a bed was available. The CSC report states – *it appears that the focus on how best to meet Stephen's needs became secondary to the asserted need to move him from the ward*. It may be that strengthened relationships between CAMHS & the general paediatric ward, in meeting the needs of children with mental health ill health, could have enabled an approach that placed the needs of Stephen as central to the decision making. That said, the pressure on inpatient beds remains a national issue. These issues are discussed in the key findings.

Ms Wilson travelled to the inpatient unit that evening but was not permitted to see Stephen (due to pandemic). She informed staff of the need for nasogastric feeds (NGFs) to be administered but learnt from staff that they were not aware of this and that they were not able to administer NGFs.

Over the next days and weeks, the inpatient unit, CAMHS and Ms Wilson raised numerous concerns with NHS England, the Local Authority and CAMHS senior management stating that the unit could not meet Stephen's needs – including concerns about inconsistent medical care, lack of trained staff to administer NGFs, delays in therapeutic treatment and concerns about physical and emotional care and hygiene. Ward staff were clear that they were not able to administer NGFs or provide any psychological input during Stephen 's admission and were struggling to meet Stephen 's complex needs. NHS England (NHSE) quickly commenced a search for a bed in a specialist ED unit and made several attempts to secure the support of a practitioner who could administer NGFs within the unit.

Practice Learning: Information sharing : Stephen's eating difficulties and need for NGFs was not included in referral made by CAMHS. The inpatient unit does not specialise in caring for children who have eating disorders. Had the referral been clear about these needs - the referral would not have met the unit's admission criteria and admission would not have been agreed. It is understood that the referral made by CAMHS complied with the relevant guidance/protocol and that the referrer was not aware of the NGFs administered in the paediatric ward and the NG tube was not in situ when the referral was made. As

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[13] This section of the act specifies the conditions under which a clinician is approved to act in these circumstances.

[14] Referrals for inpatient beds are required to follow a set process – after this process was completed, a bed was found within 2 days of the referral.

identified by a panel member: *clinical decisions are made in real time*. It is probable that the plan to administer NGFs would have been known/knowable if there had been closer consultation/joint working between CAMHS and the paediatric ward about Stephen's care. This, together with the issues raised about how well ward/medical staff feel supported by CAMHS when caring for a child with mental health difficulties, suggests that this is an area of joint working that needs to be strengthened. The daily multi-disciplinary meetings now taking place allows for closer consultation across the services involved although the impact of these meetings in improving the way in which staff on the general ward are supported is unclear – this is discussed in the key findings.

In December, a multi-disciplinary meeting took place at the inpatient unit and a Child in Need (CiN) meeting followed a short time later. Children's Services (CS) were not invited to attend the meeting in the inpatient unit and the inpatient unit did not attend the CiN meeting as staff were invited at short notice. This was a critical time in Stephen's care; coherent multiagency working was essential. Panel members spoke about *compartmentalised work* being a feature of the work that took place in Stephen's care and of this being an area that requires strengthening. This is echoed in the Children in Crisis Audit and is discussed in the key findings.

Many concerns continued to be raised about the care Stephen was receiving.[15] Concerted attempts were made by the inpatient unit to routinely administer NGFs. NHSE attempted to identify a more suitable unit and supported the unit in its efforts to ensure NGFs were routinely administered but despite these efforts routine NGFs were not provided. Stephen remained an inpatient at this unit for four weeks with few changes to the care he received.

Practice Learning: Responding to concerns in time for a child. Whilst Stephen was an inpatient at this unit, Ms Wilson frequently raised her concerns about the care Stephen was receiving. She contacted NHSE on a number of occasions and raised her concerns, she was aware that a search for a more suitable inpatient unit was underway. She was invited raise her concerns through the 'formal complaints process'. Such formal processes are often lengthy and do not result in immediate changes for a child, an immediate response to safeguard Stephen was needed. The Rapid Review and this CSPR has identified the need for concerns such as these to be dealt with in time for the child (rather than through a formal complaints process) – this is discussed in the key findings.

24/12/20: Stephen 15 years. Stephen was taken to a nearby acute hospital by staff from the inpatient unit. Clinicians at this acute hospital were concerned about Stephen's presentation including concerns about neglect and emotional abuse (relating to concerns about the behaviour of members of staff from the inpatient unit). At this time, the criminal investigation and LADO investigation commenced. These investigations concluded that there had been poor information sharing at point of referral and that the inpatient unit was not a suitable unit to meet Stephen's needs. The LADO investigation ensured that the conduct of the inpatient staff member was investigated and identified that the shortage of inpatient beds had a bearing on the situation that had been reached.

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[15] Concerns were raised internally by the inpatient unit, by Mrs Williams, by CAMHS and CS

The inpatient unit completed an investigation. This report identified that the unit was not an appropriate unit to meet Stephen's complex needs including his eating difficulties. The report was thorough but there was a considerable delay in this report being completed.

Practice Learning. Responding to concerns in time for a child. As detailed, concerns were held by practitioners in CAMHS and CS about the care that Stephen was receiving. These concerns were raised and escalated but there was no resolution. The level of concerns that were held met a safeguarding threshold – Stephen was suffering significant harm. This should have resulted in an immediate referral to the Local Authority Designated Officer[16]. Although a later referral was made, this was after Stephen had been admitted to the acute hospital and as a result was not in time for Stephen. This is discussed in the key findings.

Stephen remained in the general acute hospital for almost a month. Staff described challenges in providing care to Stephen in a general children's ward which is not set up to care for children with acute mental health difficulties. However, there was good collaborative working between the inpatient unit and the ward staff with considerable support being provided and, with the close support of a CAMHS practitioner, staff were more able to provide care than the previous acute hospital.

Practice Learning : Good Practice: Care in a general paediatric ward. Ms Wilson described the care Stephen received at this hospital as: '*brilliant – in all my dealings they have been great - he was assisted to shower and NGFs administered – there was no panic about him needing to move on – they said - he can stay until a bed is available',* this calm attitude and approach to his care provided containment and care to Stephen and Ms Wilson at an extremely challenging time – this was excellent practice. The presence, and active involvement, of a mental health practitioner on the ward has been identified by the hospital concerned as a clear factor that enabled staff to provide care to Stephen and to other children on the ward.

21/1/21: Stephen 15 years: transferred to a local inpatient unit specialising in ED.

Current: Stephen has complex needs. He has a variety of diagnoses including ASD, Obsessional Compulsive Disorder (OCD), eating difficulties, oppositional/refusal behaviours, low mood, and suicidal ideation. Caring for Stephen has presented very significant challenges. Stephen has moved from the main unit into a single occupancy annex. Various clinical formulations continue to be considered. The focus of which are on his needs relating to his ASD. Ms Wilson has encouraged staff to consider the possibility that Stephen is presenting with features of an autism breakdown – a catatonic shutdown.[17] Referral to a specialist is being progressed. The view of the unit is that the unit are unable to meet his needs, and this is consistently raised with the relevant Clinical Commissioning Group (CCG) and NHSE. However, there does not appear to be an inpatient unit that can meet Stephen's needs. Ms Wilson said she has been told

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[16] Local Authority Designated Officers are responsible for providing advice and guidance in relation to concerns raised about possible harm to a child as a result of the care provided by staff/by an organisation.

[17] *Catatonia in ASD is also referred to as "catatonia-like deterioration in individuals with ASD" (Dhossche, Shah & Wing, 2006) or "autistic catatonia" (DeJong, Bunton & Hare, 2014). The onset of catatonia in individuals with ASD is insidious; there is a marked and obvious deterioration in movement, vocalizations, pattern of activities, self-care, and practical skills (Dhossche et al., 2006). More specifically, individuals typically exhibit slowed movement and verbalizations, slowed task initiation and completion, difficulty crossing thresholds, increased reliance on prompting, passivity and lack of motivation, Parkinsonian features such as akinesia and rigidity, day-night reversal, repetitive and ritualistic behaviors, and seemingly purposeless agitation/excitement (Shah & Wing, 2006).* Catatonia in ASD https://asatonline.org/research-treatment/clinical-corner/catatonia/

– *he is in the wrong place* - by all the inpatient units Stephen has been in. A specialist ASD clinician has been appointed to work with the team and regular multi-disciplinary meetings take place to review Stephen's care and treatment. Stephen's parents, the CCG and NHSE and CS are all actively involved.

Practice Learning: Responding to Complexity: There is an absence of specialist resources/clinical knowledge about children presenting with this level of complexity. An approach of *fitting the child's needs into what a service can offer rather than services being flexible enough to fit to meet a child's needs* has been raised by panel members and by practitioners. This is discussed in the key findings.

Who is Stephen?

Stephen is a white British child. He is 16 years old and is the youngest child of his parents. Stephen has an older brother who is currently at university. Stephen enjoyed a close relationship with his brother whilst growing up. Stephen's mother and father separated when Stephen was 11. After parental separation, Stephen and his brother lived with their mother. Contact with father was maintained and both parents remain actively involved in their children's lives. Ms Wilson feels that this separation undoubtedly had an impact on Stephen as did his brother's move out of the family home to attend university. She describes Stephen's friendship group in adolescence as being dependant on his brother's relationship with peers, who would visit the family home. When his brother left for university, he lost connection with this peer group.

In his early years, Stephen was an active child who liked playing outside on his go -cart and enjoyed playing with other children. Stephen suffered with anxiety from the age of approximately seven which gradually increased over time. In early adolescence, Stephen liked technology and had a phone and Apple Watch linked to his phone. Stephen played play station, went swimming and to the gym with his dad. He enjoyed fashion and wearing clothes that were a fashion statement in line with mainstream adolescent fashion trends such as sportswear with a logo. He had aspirations to run his own fashion business and enjoyed family outings. He was interested in travelling and reading crime stories and liked to watch action films and series such as 'The Big Bang Theory' and 'The Walking Dead.' These were all expected adolescent interests and activities. But as his anxiety grew, '*it* was like *a snowball rolling that was overwhelming'*[18] and over a short while this image of Stephen faded. From the age of 14 years, Stephen has spent the majority of his life in mental health inpatient units and over this period there are several examples of experiences that would have been traumatic. Stephen is now a child who Ms Wilson describes as 'unreachable'**:** **'***He is now in a dark place – I cannot see how he can come back from this place – he is shut down – he is traumatised.'*

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[18] Ms Wilson

Key Learning

1. Prevention: promoting emotional health and wellbeing/responding to emerging mental health needs

The system was unable to put the brakes on at an early stage.[19]

Introduction. It is an undisputed universal truism that prevention is better than cure. There is nothing new about this concept - it is a fundamental principle of modern health care and inherent within health and social care strategies across the UK. It is impossible to say with any degree of certainty that responding to Stephen's needs differently at an earlier point would have prevented his difficulties escalating. However, as the timeline of events has shown, there were opportunities to provide a different response to Stephen and his family which may have influenced the course of events and may have 'put the brakes on at an early stage.'

CSCP recently completed an audit[20] of 10 children's cases, who had experienced a mental health crisis, with the purpose of exploring how supportive measures in the community may assist in preventing escalation of mental health difficulties which require high level support and possibly inpatient care. This audit identified the importance of early intervention and the opportunities/reachable moments that were missed for children whose cases were the subject of review. The following is a summary of the 'reachable moments' in Stephen's life that were missed.

Early intervention - the importance of transition: Stephen was seven when he started to suffer with anxiety, and this escalated during early adolescence. During this time Stephen experienced the living losses of parental separation, his brother's move from the family home and the later loss of a school community. A particular milestone was his transition to secondary school. Support was put in place at the secondary school to assist Stephen in this transition, but it appears that possible difficulties in transition were not fully addressed in primary school. Practitioners at the learning event spoke about the differences in how this transition is supported across local primary schools and spoke about the need *for enhanced support for transition from primary schools however insignificant a child's needs may seem* and that this should be consistently provided across schools in the local area.

Recommendation 1 : The CSCP to seek assurances that primary schools in the local area are routinely identifying children who may struggle with transition and that these children are supported/prepared for transition at an early point. A particular focus should be on children with symptoms of/diagnosis of an ASD.

Early intervention – CAMHS.

Areas need to think and plan carefully to ensure that children get support when awaiting a service from CAMHS. They also need to ensure that children are offered alternative services when not meeting the threshold for CAMHS.[21]

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[19] Panel Member

[20] Coventry Safeguarding Children Partnership Audit & Performance Subgroup Children in Crisis Audit 2020

[21] *'Feeling heard': partner agencies working together to make a difference for children with mental ill health*. Joint Targeted Area Inspection December 2020

Stephen was referred to CAMHS when he was 10 and first seen in CAMHS when he was 13 (the month of his 14th birthday). Over 3 years had passed since the referral. Ms Wilson described a rapid deterioration in Stephen's anxiety and behaviour over this time. Stephen engaged well with CAMHS and attended each appointment he was offered. By this point, Stephen was entering adolescence - his emotional difficulties had been present for over 5 years.

The reason for the long waiting lists in CAMHS is that there is, and continues to be, a high demand for CAMHS. Thresholds are high and the reality is that finite resources limited the preventative reach of this service at the time. Practitioners at the learning event questioned the overreliance on CAMHS to *fix the problem (*when children are presenting with emotional needs)… *it is not realistic that CAMHS can support the whole gambit of mental health issues.* It is understood that since this time Tier 2[22] CAMHSs have been commissioned (such as the Social Emotional and Mental Health Team) providing targeted support to children and young people. However, it seemed that the range of emotional wellbeing services available for children in the local area is not well understood.

Early intervention – Children's Services (CS). Meeting Stephen's needs fell to his parents, the school and to CAMHS. Services were working in relative isolation from each other and from multi-agency partners. The timeline of events describes the long-standing concerns about Stephen's wellbeing and describes the times at which a referral to CS was a necessity but did not happen. At the point of crisis, when plans were in place for Stephen's inpatient admission, a referral to CS was discussed with Ms Wilson. Ms Wilson was unclear about the nature of support that could be provided by CS and as a result consent for referral was not gained.

The complexity of Stephen's needs meant that no one agency could have possibly met these needs. The importance of a multi-agency approach to meet the needs of children with an ASD and/or mental health needs is set out in statute[23], inspections[24] and relevant Serious Case Reviews[25]. The central issue about gaining informed consent has been raised in this case and in other cases. These cases highlight the need for practitioners/services to understand and promote the importance of multi-agency working.

The Children in Crisis (CIC) Audit identified the need for early referral to CS/early help to provide the right support at the right time to try and prevent future escalation of difficulties. No specific recommendation was made about this issue.

Recommendation 2 : The CSCP to determine what may need to be done to strengthen multi-agency working with children who have mental ill health which should include addressing the need for services to regard mental ill health as a safeguarding matter and establishing how informed consent for referral to CS will be achieved.

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[22] **Emotional wellbeing and mental health services for children are provided in a series of tiers. Tier 1** is early intervention and prevention provided through universal services such as schools, health visitors, school nurses, GPs, Youth Connexions, helplines and websites for support with general emotional wellbeing. **Tier 2** means early help and targeted services. Support is provided by a practitioner in the community and may be through community counselling, counselling or mentoring in schools, education psychologists, education support centres, targeted youth support teams. **Tier 3** means specialist CAMHS in the community provided by a multi-disciplinary team. **Tier 4** means specialised day and inpatient units, where people with more severe mental health problems can be assessed and treated..

[23] Such as : The Mental Health Act 1983 & The Children's Act 1989.

[24] Such as : '*Feeling heard': partner agencies working together to make a difference for children with mental ill health.* Joint Targeted Area Inspection December 2020

[25] *Teenagers: learning from case reviews briefing*. NSPCC Feb 2021

1.1 Prevention - Meeting the needs of children with ASD.

As detailed in the timeline of events, Stephen was on a waiting list for a neurodevelopmental assessment for three years before he was seen and diagnosed with ASD. The view of Ms Wilson is that this delay was critical: *'his difficulties spiralled',* and that this delay in assessment contributed to the later development of his complex mental health needs.

The CIC Audit identified that of the 10 children in the audit cohort 5 of the children had a diagnosis of ASD or were waiting for an assessment, and practitioners identified that the long waiting times were problematic. The view of the audit panel members, and some panel members/practitioners, was that diagnosis per say is not the key issue. ..*the panel were in agreement that diagnosis can often be a barrier to receiving support and the focus needs to be on interventions, strategies and reasonable adjustments in order to achieve better outcomes for children and young people.*[26] Whilst this principle is accepted, there is an alternative view held by Ms Wilson that the lack of diagnosis meant that she struggled to understand his behaviour and felt unsupported and at a loss to effectively respond. Without a diagnosis there was a risk that Stephen was seen to be behaving badly and it was difficult for family members, peers, the school, and the community to make sense of Stephen's needs, and for Stephen to make sense of himself. This was particularly important for Stephen as he approached adolescence when a sense of identity and belonging is such an important part of adolescent development.

The relevant NICE guidance[27] states that the ASD assessment should start within 3 months of referral. This is rarely kept across England and Wales and although there are variations in waiting times, the national picture suggests that the wait can be considerable.

In 2019, the British Medical Association examined the waiting times for ASD assessments and the impact of delay. [28]

The FOI data that is available also show that both average and the longest waiting time for assessment are badly failing children and young people……The potential impacts of a delayed diagnosis on a child's development are alarming and conversely the benefits of an early diagnosis are wide-ranging.[29] [30]

The report outlines the following impacts:

- Access to education
- *Lack of diagnosis denies a child or young person the opportunity to understand the factors that are causing them to respond in a specific way. For families this can create undue stress, with their child's response to the world often misinterpreted as poor behavioural issues.*
- *A delayed diagnosis may lead to mental health conditions going undiagnosed. While not always related, it is estimated that around 70% of people on the autism spectrum also*

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[26] Coventry Safeguarding Children Partnership Audit & Performance Subgroup Children in Crisis Audit 2020

[27] *NICE Assessment and diagnosis of autism: what to expect.*

[28] *Failing a generation: delays in waiting times from referral to diagnostic assessment for autism spectrum disorder* (BMA 2019)

[29] Elder J H, Conseulo M K, Brasher S N et al (2017) *Clinical impact of early diagnosis of autism on the prognosis and parent-child relationships. Psychology research and behavioural management*. 10: 283–292

[30] Zwaigenbaum L, Bauman L M, Stone W L et al (2015) *Early identification of autism spectrum disorder: recommendations for practice and research.* Pediatrics. 136(1): S10-S4

have a co-concurring mental health condition[31]. A failure to recognise and understand related conditions will delay access to early intervention or prevention services.

- *Delayed waiting times are associated with increased financial costs, caused by, for example, failing to address the link between ASD and associated mental health conditions.[32]*

There remain long waiting times for an ASD assessment in the local area which can exceed 3 years. It is understood that there has now been significant investment in this service to enable these waiting times to be reduced. However, it is early days in the development of this service. Since the period under review, a local 'Children's Community Autism Support Service' (CCASS) is available for children and young people who have a diagnosis of ASD or who are waiting for an assessment by the NDT. This early intervention service is a promising development, the support on offer includes 1:1 sessions and social groups with children and training and toolboxes for parents/carers and professionals. However, as discussed in the next section, this is not available for children in Stephen's circumstances.

The views of panel members was that more needed to be done to prevent Stephen's subsequent admission to hospital and that a strengthened health service provision is needed to support children in the community who have an ASD diagnosis and/or are suffering from mental health difficulties. The new developments (detailed above) are promising.

The Clinical Commissioning Group (CCG) Transforming Care Service[33] was identified as an important service for Stephen. The aims of this team are to; improve quality of care for people with learning disability and/or autism; improve the quality of life for people with a learning disability and/or autism; enhance community capacity, thereby reducing inappropriate hospital admissions and length of stay.

A referral was not made to this service until the beginning of 2021. It seemed that the reason for this was due to the criteria for acceptance; the service do not work with children where CAMHS is actively involved in providing therapeutic treatment or when CS are involved. Equally, Stephen would not have met the criteria for support from the recently established Children's Community Autism Support Service (CCASS), as the criteria for acceptance by this team is the same.

Information provided by the Transforming Care Team to this review suggested that the team would not have been involved with Stephen in the community as the team only provides services *when admitted to hospital[34]*. This is clearly incorrect as the literature is clear that this is also a preventative service albeit only in certain circumstances (as above). The work of this service was not widely known to practitioners and there seemed to be confusion about the work of this service and about how to navigate through the services for children who have a diagnosis of ASD or who are waiting for a diagnosis. This apparent confusion about the services is important; if practitioners find navigation problematic then it is likely that

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[31] MIND (2015*) Supporting people living with autism spectrum disorder and mental health problems: a guide for practitioners and providers*. London: MIND

[32] *The National Autistic Society have estimated that investing in ASD diagnosis would lead to cost savings for the NHS of up to £337 million over five years, from reduced spending on mental health services.*

[33] *Transforming Care is not a pathway or a service. It makes available resources and support if a child or young person has a diagnosis of autism or a learning disability and is in crisis and at risk of being admitted to hospital.* CSCP One Minute Guide. Learning Disability and Autism Programme.

[34] CSPR DW CCG CWPT Transforming Care Team Agency Report 2021

this confusion is felt by parents/carers. This confusion about the services on offer was apparent when speaking with Ms Wilson.

The CIC audit identified a lack of knowledge about ASD services and made the following recommendation: *to strengthen the intelligence and understanding amongst professionals across all agencies of the Transforming Care Pathway and the support that is available to the cohort of children with a diagnosis or suspected ASD or Learning Disability.* It is understood that a briefing has been produced and disseminated although it seems that confusion about this service remains.

Recommendation 3. The CSCP to maintain an active overview of the waiting times for ASD assessment in the local area and provide support and challenge to the CCG in the reduction of waiting times. CSCP to share the learning in this report with the Learning Disability and Autism Executive Board (LDAEB) and provide support and challenge to this board in the implementation of the relevant CIC recommendation. This should include a requirement to strengthen an understanding by multi-agency services, parents/carers, and children about the services available and any gaps. Outcomes to be measured by LDAEB and reviewed by CSCP.

2. EHCPs and the importance of school life

As Stephen's anxiety, physical and mental health needs increased, the school (which had made significant adjustments to accommodate his needs) felt unable to manage these needs. In December 2019, Stephen's attendance was reduced to part time and less than two months later he was no longer attending. Ms Wilson has identified a clear and rapid deterioration in his mental health and wellbeing from this point - Stephen was admitted to an inpatient unit approximately one month later. Within a period of 4 months, Stephen had gone from a child who was regularly attending school, had a full vocabulary, had aspirations and interests, attended family outings, was eating and attending to his self-care to a child in an inpatient unit where his needs were identified as both complex and challenging to meet – he was mute, unable to attend to his self-care and refusing to eat.

It is not being suggested that this decline was a result of a change in school routine/absence of a school place. Multiple factors influencing this decline have already been mentioned. However, it is important to acknowledge the intrinsic multi-faceted value of school attendance. The importance of schools in the lives of children and the impact on children of not being in school has been raised in numerous Serious Case Reviews/CSPRs, government guidance[35] and in relevant Joint Targeted Area Inspections (JTAIs)[36]. This is relevant for all children but especially vulnerable adolescents who may have complex mental health needs. Yet these children are at greatest risk of being without a school place.[37]

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

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[35] *TIMPSON REVIEW OF SCHOOL EXCLUSION* May 2019. Presented to Parliament by the Secretary of State for Education by Command of Her Majesty

[36] Such as: '*Feeling heard': partner agencies working together to make a difference for children with mental ill health*. Joint Targeted Area Inspection December 2020

[37] *School exclusion: a literature review on the continued disproportionate exclusion of certain children*. DfE May 2019

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 supported by the resources and the statutory framework provided by an Education Health and Care Plan (EHCP) for children such as Stephen.

School staff have commented that there was little more that could have been provided for Stephen at school and considerable efforts were made to enable him to attend. However, as identified in the timeline of events, the need to start the process of a EHCP assessment as soon as possible for children such as Stephen cannot be emphasised enough.

The need for an EHCP was identified by the NDT, by CAMHS and later by the first inpatient unit as part of discharge planning. It is important to note that any of these services could have referred Stephen for this assessment, but this did not happen - an EHCP has only very recently been put in place. The view of practitioners was that: *Children seem to have to be in a crisis before a request is made for a statutory EHCP assessment*. The education report provided to this review identified that Stephen needed enhanced support at school, and *this could have been provided through an EHCP earlier in his school life.* The CIC audit has identified that of the 10 children who were the subject of the audit – only one of these children had an EHCP.

In responding to the learning identified in a relevant serious case review[38] a revised Education Health and Care Needs Assessment (EHCNA) strategy has been implemented in Cambridgeshire that recognises the rights of children with significant mental health difficulties and their entitlement to an EHCNA. Some considerable work has taken place to raise awareness within schools about the importance of EHCPs in meeting the needs of children such as Stephen and to ensure that, when children are inpatients in mental health units, an application is made for an EHCNA at the point of admission to expediate the process of assessment (with the aim to complete assessment as close as possible to the date of discharge).

No recommendation was made in the CIC audit relating to EHCPs therefore the following recommendation is made to support the findings of this audit and this CSPR.

Recommendation 4. Coventry local education services to review the current EHCP strategy to ensure that the importance of EHCPs for children with ASD and/or mental health needs is adequately set out, and that an assessment is commenced at the earliest possible point. This strategy should reflect the urgent need for an EHCPA to be expedited for children at the point of admission to an inpatient unit. Awareness raising about the importance of EHCPs to be completed with schools and multi-agency partners. CSCP to oversee implementation and provide support and challenge.

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[38] Sam Gould Serious Case Review. Cambridge and Peterborough Safeguarding Children Partnership Board 2021

3. Responding to complexity: In the community

There is a lack of available resources/expertise within the community to meet the needs of children presenting with ED, ASD and OCD.[39]

His journey through the system has been horrendous – the system continues to fail him. There is a need to better understand and respond to the vicious cycle of ASD/OCD/ED. There is nothing worse than feeling no-one knows what to do – it must be scary for Stephen .[40]

The struggles to meet Stephen's needs in the community were evident, these struggles echoed across multi-agency services and remain unresolved. *Identifying appropriate provisions to meet Stephen 's needs (community and inpatient) has been highly challenging, particularly identifying services that can meet his holistic needs. There have been particular challenges in meting needs arising from autism and eating disorders together.*[41]

Panel members and practitioners identified that the lack of specialist resources to meet the needs of children with complex needs is a national issue affecting children and families across the country. Service provision to children is typically split across service lines that delineates needs and thresholds. Each service will have a marked boundary about what level of need a service will respond to, and each service will typically categorise need to determine whether the service is the right fit and refer to specialist teams when indicated/where such services exist.

A more flexible approach to commissioning both community based, and tier 4 services would be beneficial in terms of meeting the needs of individual children and young people. There is a need to be able to wrap services around children and young people as opposed to trying to identify which service criteria children and young people with complex needs 'fit into'.[42]

It's vitally important that children and young people with severe complex needs, and their families and carers, have access to joined up services that can provide them with the support they need. Without efficient coordination, people can be passed from service to service depending on their needs and important information about the support they require can slip through the cracks.[43]

Relevant NICE guidance has now been published.[44] This guidance is focussed on children who have severe complex health needs or disabilities. Children like Stephen, who have ASD and/or severe mental health needs, meet the criteria of having a disability and therefore come under relevant legislation, guidance, and specialist service provision. However, as identified by panel members, practitioners and Ms Wilson, the needs of this specific group of children are at risk of not being seen to fit into the legislation and

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[39] Panel members and practitioners

[40] Ms Wilson

[41] Children's Social Care CSPR Agency Report 2021

[42] Children's Social Care CSPR Agency Report 2021

[43] Dr Paul Chrisp, director of NICE's Centre for Guidelines. Draft guideline on disabled children and young people up to 25 with severe complex needs. NICE August 2021

[44] Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education. NICE Guidance March 2022

guidance about children with physical or learning disabilities and therefore the range of possible entitlements[45] are not promoted by services/practitioners.

Recommendation 5. The CSCP to request that partner agencies review their approach to children with severe complex needs arising from ASD and/or mental health needs in the community and demonstrate how the workforce are suitably equipped to respond, how relevant disability guidance and legislation is effectively used to meet a child's needs, including how relevant specialisms are engaged where needed and how bespoke care placements are commissioned.

3.1 Responding to complexity: Availability and suitability of care: general hospital wards and inpatient units

He is in the wrong place – we are working in a system that cannot meet his needs…..There is nowhere in CAMHS/T4 that deals with the complexity of this type……. The lack of availability of T4 inpatient beds is a national issue.[46]

Each of the inpatient units reported that they were unable to meet Stephen 's needs; the first inpatient unit was clear that they were unable to meet all of his needs, the second inpatient unit were so unable to meet his needs that *although wilful neglect had not occurred, Stephen has ultimately suffered from neglect whilst in an institutional setting,*[47] the final inpatient unit has struggled to meet his needs and are clear that it is not the right place for Stephen . Despite extensive searches, it seems that there is no 'right place' that can meet Stephen 's needs.

It is important to mention the views of clinicians about inpatient care. CAMHS practitioners were clear that *inpatient care is not a panacea – there is an assumption that it is – but for children, particularly for children with ASD, it is very challenging environment and can feel overwhelming.* Their view was that investment in prevention is needed but that children currently in crisis cannot wait for these changes to be made - *there is an urgent pressing need for there to be greater availability of suitable mental health inpatient beds.*

The view of CSCP is that Stephen suffered significant harm as a direct result of the lack of availability and suitability of inpatient beds. The LADO and criminal investigation identified that this directly contributed to the harm Stephen suffered and the lack of inpatient beds was the most consistent learning identified by panel members in this CSPR. Practitioners spoke passionately about this; clinicians seemed worn out by this shortage which was described as *the biggest work stress that has been going on for decades*. At the time Stephen was waiting for an inpatient bed, 11 other children in the local area were also waiting for a bed. These children almost invariably wait for a bed whilst they are an inpatient in a general hospital paediatric ward. As identified by panel members and practitioners, and as evidenced by Stephen's experiences, these environments are often unsuitable for these children. It can be an extremely difficult time for the child, the family, other children on the ward and staff.

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[45] Such as: Entitlement for suitable adaptations to be made by services as set out in The Equalities Act 2010. Financial support such as the Disability Living Allowance, Carers Allowance, Personal Independent Payments, access to a range of services provided by Children's Services such as respite care, recreational activities and home adaptions.

[46] Panel members

[47] CSCP Rapid Review Report

NHS England is responsible for commissioning inpatient beds and was represented on the panel and at the practitioner learning event. It is understood that NHS England has recognised these problems. Consultation with children and young people with mental ill health, their families and carers resulted in NHSE concluding that (they) …*have made it clear that more services should be provided in the community and that, where an inpatient stay is required, it should be as short as possible. They have also made clear that it is unacceptable for some young people to travel excessive distances, be placed inappropriately on paediatric acute or adult wards, or struggle to access inpatient care at all.*[48]

The Mental Health Implementation Plan sets a whole systems modernisation of children and young people's mental health services (CYPMHS) including; working towards 100% coverage of 24/7 crisis provision for children and young people by 2023/24, provision of community forensic CAMHS in local areas and delivering improvements in the direct commissioning of inpatient beds. A new taskforce has been set up to improve specialist children and young people's inpatient mental health, autism and learning disability services in England with the Children's Commissioner for England chairing an independent oversight board to scrutinise and support the work of the taskforce. These service changes were set out in 2019 but the pace of change was not in time for Stephen . Whilst changes are awaited, the local area has set up daily multi-agency meetings, which include NHS regional representatives, to provide the best possible care to children in Stephen's circumstances. This has proved to be helpful in mitigating, as far as possible, the problems that were inherent in Stephen's case. However, these are national issues that require a national response and there are limits to the local changes that can be made. The Rapid Review held in June 2021 identified relevant national findings:

- At a national level consideration needs to be given in relation to how to solve the national Tier 4 bed crisis
- At a national level guidance needs to be produced for dealing with children with complex needs on a general paediatric ward which includes consideration on how to safeguard children who may be admitted for general medical procedures

Recommendation 6.
Coventry and Warwickshire Integrated Care Board to provide regular updates to CSCP about service developments in the relevant areas set out in the Mental Health Implementation Plan and seek seek assurances that inpatient mental health provision can support / make reasonable adjustments to accommodate patients who have ASD & severe complex needs.

The findings of the Rapid Review, and the national drive to implement whole system changes to children and young people's mental health services, suggest that the problems about availability and suitability of mental health inpatient beds are well known. This was echoed in the CIC Audit. However, at the time of this CSPR, the issues appear to remain unresolved. Given the ongoing impact of these service gaps on children across the country it is felt important that the National Panel take an active interest in this safeguarding matter. Therefore, the following recommendation is made:

Recommendation 7. The CSCP make representation to the National Panel about the need to conduct a National Review on relevant matters highlighted in this CSPR about the lack of availability and suitability of mental health inpatient units for children.

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[48] https://www.england.nhs.uk/mental-health/cyp/children-and-adolescent-mental-health-service-inpatient-services/

In addition, the Rapid Review highlighted the unsuitability of general paediatric wards for children in a mental health crisis and identified the need for national guidance regarding safeguarding children on general paediatric wards. The Think Family Outreach Team is now in place to support children and families in these circumstances, and this is a good service development. However, there remains a need to understand why there was a distinct difference in how staff felt able to manage Stephen's needs in the different acute hospitals and what staff on general paediatric wards need to support them in these circumstances. Therefore, it is important that the CSCP tries to get beneath these issues so that the needs of front-line staff in these circumstances are better understood – this should include an understanding of how the organisational cultures and hierarchies may help or hinder staff in their work.

Recommendation 8. The CSCP to seek assurances that the support provided to staff on general paediatric wards enables the best possible care to be provided to children suffering from a mental health crisis. This support should include support to meet a child's needs, support in meeting the needs of other children on the ward and in contending with the impact on their own wellbeing.

4. Safeguarding a child from significant harm

Day one it was clear that his needs could not be met - one month later – he was admitted to hospital when he was described as 'emaciated'.[49]

As described in the timeline of events, Ms Wilson had significant concerns about the care Stephen was receiving at the second inpatient unit on the day of his admission. At the start, the unit were clear that staff were not able to administer NGFs. As the days and weeks passed, additional concerns were routinely raised by Ms Wilson, the inpatient unit, CAMHS and CS about the ability of the unit to meet Stephen's needs. Concerns were escalated by staff to senior management and Ms Wilson frequently contacted NHSE detailing her concerns. There were concerted attempts by the inpatient unit and NHSE to seek support from the wider NHS system to meet Stephen's needs; additional financial assistance to the unit was provided and proactive searches for a suitable inpatient bed took place. Despite these efforts, and despite the escalation of concerns by the inpatient unit and by the agencies involved, little changed for Stephen. It was only at the point of medical crisis that Stephen left this unit and was admitted in an emergency to a general paediatric ward for urgent medical treatment.

The Rapid Review concluded that: *He was suffering from significant emotional harm and neglect.* Stephen was a vulnerable child in institutional care, compulsorily detained with little contact with the outside world. There is a plethora of research evidencing the impact on children of neglect and emotional harm. At minimum, the significant harm he suffered would have compounded his mental health needs and caused additional distress.

The question that arises is: Why did this happen and why nothing changed for Stephen? The fact that this inpatient unit was not equipped to meet his needs, and that the original referral did not specify his needs relating to NGFs, has been discussed. The fact that Stephen 's needs were complex and there is a lack of inpatient units able to provide care to children with this level of complexity has also been discussed. In

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[49] Ms Wilson

addition, this happened at a time of the coronavirus pandemic - this systems dynamic would have undoubtedly added a further complicating layer.

However, whilst all these contributory factors are understandable, the issue still remains that a child was suffering significant harm, and this was known. It seemed that the system was unable to make changes in real time despite the concerns being escalated to the highest levels. Alternative provision was sought but there were no other inpatient provider beds available that could meet Stephen 's complex needs. The terms of reference for this review questioned the effectiveness of the escalation pathway in NHSE. It is clear that escalation across the agencies was not effective and making changes to escalation pathways in these circumstances is unlikely to yield systematic changes.

The central question that arises is: What else could have been done to protect a child from harm in these circumstances? The relevant legislation that applies to these circumstances is the Children Act 1989. This sets out a duty to protect a child from significant harm and the actions needed.

The Rapid Review identified relevant learning:

- When Tier 4 placements have a child or young person placed whose needs they cannot meet they need to clearly escalate their concerns.
- NHSE should have procedures in place to ensure that any concerns about a Tier 4 placement not being able to meet the child or young person's needs are acted upon immediately.[50]

The following recommendations are made in this CSPR to locate these findings within the relevant legislation and thereby provide a statutory foundation.

Recommendation 9. The CSCP to review whether the role of the Local Authority in leading investigations into concerns about significant harm to children as a result of the care provided in an institutional setting under Sc47 of The Children's Act is clearly understood and seek assurances that this crucial role is sufficiently understood and prompted across multi agency partners.

Recommendation 10. NHSE, and relevant providers of commissioned care, to review the practice and processes of responding to concerns about a child in real time and to demonstrate to CSCP their compliance with their relevant safeguarding duties under the Children Act 1989. Commissioning practices should adequately reflect this requirement.

5. Governance and assurance

The previous section has outlined the actions that need to be taken in real time to safeguard a child from harm. This section discusses the actions that are needed to provide robust safeguarding governance and assurance after a significant safeguarding incident has occurred. The first issue highlighted by this case relates to the requirement to submit serious incident (SI) notifications and to complete internal enquiries by means of a serious incident report (SIR).

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[50] It is important to note that this CSPR has established that concerns were acted upon by NHSE and alternative provision was sought. However, there were no other inpatient provider beds available that could meet Stephen 's complex needs.

The NHS Serious Incident framework describes the process and procedures to help ensure serious incidents are identified correctly, investigated thoroughly and, most importantly, learned from to prevent the likelihood of similar incidents happening again.[51]

This framework applies to all NHS funded care, including independent sector organisations providing NHS funded services. The second inpatient unit is such an organisation. On starting this CSPR, a copy of the SIR was requested. This SIR did not meet expected standards, and this had previously been raised by NHSE with the provider.

It is important to note that NHSE responded to this significant incident by way of direct and active overview of admission to the unit to ensure the needs of children were being met. However, despite chasing, no satisfactory SIR had been received at the point of this CSPR commencing. At the insistence of CSCP, an SIR was finally submitted in February 2022. The report is thorough, complies with expected standards and identifies relevant learning for the organisation. However, this report was written and submitted over 12 months after the significant incident. Over this period, the unit continued to be commissioned by NHSE to provide inpatient care to children. It is understood that a number of relevant issues were pursued with the provider at the time to provide assurances that service changes had been made to ensure other children did not suffer the same harm as Stephen. However, without an SIR, it was not possible for NHSE to be sufficiently assured that any potential systemic issues had been addressed (which may have compromised the quality of care provided to children in the unit). It is understood that concerns had been raised by NHSE with the provider about the lack of an SIR and that the impact of the pandemic and flux in staffing levels at the time led to delay. Panel members questioned whether a contributory factor was also the lack of availability of mental health inpatient beds.

Recommendation 11. NHSE to provide assurances to CSCP that all providers of treatment and care to children within mental health inpatient units submit an SI notification and SIR that meets expected NHSE quality standards, including the quality of the report and the timeliness of submission, and set out what action will be taken if these standards are not met.

A further governance and assurance issue relates to the notification of serious incidents to CSCP. The notification about Stephen's case was made to CSCP five months after he was admitted to the general paediatric ward suffering from significant harm. There were an array of multi-agency services involved with Stephen at this time (and over the following months) all of whom had a responsibility to refer this case to CSCP.

Recommendation 12. The CSCP to review referral pathways for notifying CSCP of serious incidents, including incidents involving children placed out of area, and raise awareness of the requirement to make timely referrals.

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[51] https://www.england.nhs.uk/patient-safety/serious-incident-framework

6. Collaboration across the multi-agency system

There was little collaboration and no holistic approach to meeting Stephen's needs.[52]

Panel members and practitioners were clear that: *there is no such thing as a magic wand… no single agency has the solution…. we bounce children around the system* and there is no such thing as a service that could have provided the answer to meeting Stephen's needs…. *Flexible and creative multi -agency collaboration at the front line and across the organisational hierarchy is needed.* The need for multi-agency working, to potentially prevent Stephen's difficulties escalating, has been discussed. This section explores collaboration across the multi-agency system after Stephen's first inpatient admission. Multi-agency reports submitted to this CSPR identified several areas where multi-agency collaboration was fragmented:

- Multi-agency collaboration and joint planning on admission and discharge at the 2 inpatient units
- No medical handover of information from the general paediatric ward to the 2nd inpatient unit at the point of transfer
- During key meetings at the inpatient units, CSC & CAMHS were not always invited/ did not attend.
- No medical handover of information from the 2nd inpatient unit to the 2nd general paediatric unit at the point of Stephen 's admission
- No care plan shared by the 2nd inpatient unit with the general paediatric hospital or with the 3rd inpatient unit for some considerable time.
- Multi- disciplinary team meetings were inconsistent across the timeline (although recently improved).

The CIC audit identified examples of good multi-agency working but concluded that: *collaborative working and joined up working between services is an area for development*. The need to improve collaborative working for children with mental ill health has been identified as a national issue in several reports including the Joint Targeted Area Inspection of services provided to children with mental ill health: *Children's mental ill health cannot be addressed by any one agency working in isolation. Partners need to come together at a strategic level, alongside those who use the service, and develop a joined-up and coherent approach and ensure that services are delivered in an integrated way at the frontline.*[53] This inspection identified that multi-agency collaborative work *can be really effective when professionals work to a shared practice model* and that local partnerships have an important part to play in developing this work.

Since the time under review, it is clear that multi-disciplinary and multi – agency working has significantly improved and there is now effective collaboration in Stephen's care and treatment. However, this now needs to be formalised for all children with mental ill health. The CIC Audit did not make a relevant

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[52] Panel Members

[53] Feeling heard': partner agencies working together to make a difference for children with mental ill health. Joint Targeted Area Inspection December 2020

recommendation. Therefore, the following recommendation is made to strengthen the current service developments in working with children with mental ill health/complex needs.

Recommendation 13. The CSCP to issue a framework of expected multi -agency working based on the recommendations from the recent JTAI and the good practice currently in place in the care and treatment of Stephen - this framework should include how joint working will be achieved at the front line and across the organisational hierarchies.

7. Stephen's voice

It has proved difficult to find Stephen's voice in agency records. Over the past 16 months Stephen has not spoken, and this provides a partial explanation. Therefore, it has been important to interpret Stephen's voice through his behaviour. As part of this CSPR, Ms Wilson and practitioners were asked what Stephen may want to say about his life, his care and treatment. Sadly, practitioners and Ms Wilson have said that Stephen would probably say that he wants to be left alone to die.

For obvious reasons, it is simply not possible for practitioners to honour these wishes and without doubt the current treatment Stephen receives, involving frequent restraint to try and keep him alive, is against his wishes. This is an immutable tragedy for Stephen and his family, and it is clear that this presents significant emotional dilemmas for the practitioners involved in his care.

Speaking to Ms Wilson and school staff (who knew Stephen before he became mute) said that Stephen was a quiet child who rarely spoke about his feelings although it was clear through his behaviour what he was communicating about his wishes and feelings and when he found someone he could trust - Stephen's spoken voice was heard. Stephen found such trusted people at school and in the 1st inpatient unit. One example being the excellent work completed by an occupational therapist at this unit who Stephen clearly trusted. Ms Wilson spoke about how he found someone he trusted whilst in the 3rd inpatient unit and although mute at this time - *he would whisper to them*. Changes in care arrangements and staff turnover meant that these relationships were lost.[54]

It is accepted that sustaining trusted relationships can be challenging and bringing a focus to the voice of a child can be difficult, this is identified as a national issue : *It sometimes seemed that the complexity of the children's lives was overwhelming professionals, meaning that they did not focus on the voice of the child and the impact of the children's experiences on their mental health.*[55]

Inspections, practice guidance,[56] research and various SCRs/CSPRs have repeatedly emphasised the importance of trusted relationships to enable a child to give voice to wishes and feelings and to feel heard. The local CIC audit identified the importance of trusted adults as clear learning. The recommendation currently being enacted is focused on building these relationships in schools. The Rapid Review identified the need for practitioners to record the voice of the child in agency records and action is being taken to progress this learning. The following recommendation is made to support the work currently taking place

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[54] It is promising to note that more recently there are some early signs that Stephen is staring to engage with a trusted adult and demonstrating that this is a trusted adult through his body language although he remains mute.

[55] *Feeling heard': partner agencies working together to make a difference for children with mental ill health.* Joint Targeted Area Inspection December 2020

[56] Such as: *Developing and leading trauma-informed practice.* Research in Practice Dartington 2018

in Coventry to extend this work to promote the importance of trusted relationships in all settings to enable a child's voice to be heard.

Recommendation 14. Mental Health Surge Group to extend current work related to trusted adults to include all agencies. CSCP to include the importance of trusted adults in the multi-agency framework for children with mental ill health/complex needs.

8. Advocacy

The terms of reference for this review posed a question about how family members were able to advocate on Stephen's behalf. As part of this CSPR, there has been extensive discussions with Ms Wilson about his care and treatment. Throughout Stephen's life, it is clear that Ms Wilson has done everything in her power to advocate for Stephen's needs. Navigating the multiple systems has been extremely complex and has taken sheer tenacity, courage, and immense personal resources to achieve this. At times, she has been heard. At other times, she has felt she has been in a constant battle to be heard and there have been times when she has been ignored. Of particular note was when Stephen was at the 2nd inpatient unit when she tried everything in her power to be heard - to no avail. This report outlines how concerns about the care a child is receiving should be responded to in real time. In addition, this CSPR has found that more needs to be done to take a human approach, rather than bureaucratic stances, when hearing the voice of parents.

In addition, there is a legal requirement for inpatient mental health facilities to provide an Independent Mental Health Act Advocate for children detained under the Mental Health Act and/or an Independent Mental Capacity Advocate for children who are deemed to not have capacity to be able to make an informed decision about their treatment. This did not seem to be understood. Therefore, the following recommendation is made.

Recommendation 15. In line with legal requirements, children in inpatient mental health units must be offered an independent advocate to support the child and the multi-agency system in hearing a child's voice and advocating for them. CSCP to maintain oversight.

9. The emotional burden of care in a fallible system: Supporting parents and staff.

It feels like a living grief that does not end.[57]

Living with a sad, angry, sometimes aggressive child who is overtaken by ritualised behaviours, is restricting eating, highly anxious, self-harming and making attempts to end their life, is traumatic. The nature and extent of the behaviours are not single incidents, but ongoing lived experiences that can saturate every part of family life, often for many years. Parents/carers need consistent and empathetic support and understanding if they are to meet their children's needs in the short and long-term. Professionals need to help parents hold on to feelings of self-worth and self-esteem by valuing them and the contribution they have made, and continue to make, to their children's lives.

In the early years, when Stephen had a diagnosis of ASD/ before his admission to inpatient units, there was little seen in agency records showing how parents were engaged by practitioners in the work that

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[57] Ms Wilson when speaking to the Lead Reviewer and the Chair of the CSPR

was completed with Stephen. It is appreciated that the pandemic impacted on the work that could have been completed from March 2020. However, it seemed that before this time, whilst there was good communication with Ms Wilson by CAMHS, it did not appear that family work was completed. This was important not only to support Ms Wilson, Stephen's father and brother, but also to understand Stephen within the context of his family and the system of interaction between family members.[58]

Think Family is an important aspect of providing services to children, this can be facilitated in the community by the provision of family therapy through CAMHS but also through the involvement of early help services/children's services where child and family assessments enable a wider view of family relationships and support that may be needed. Therefore, it is important that a whole systems approach is used to enable a child to be seen in context, and for the support system around the child and family to be as systemic and creative as possible. In the absence of this approach, there is a risk that a child's needs are primarily seen through the lens of their diagnoses/labels (which is at risk of defining them and the services provided) rather than seeing the whole child in the context of their environment.

Passionate, compassionate, and empathetic staff. A wealth of evidence has been seen demonstrating the commitment of front-line staff to Stephen - the quality of care they have provided has been impressive. The exceptions have been outlined but these exceptions were not replicated across the system. Overall, it has been deeply touching to read about examples of outstanding care and compassion in some of the most challenging of circumstances.

The challenges for staff have included not only providing care to a child who is clearly in pain and is projecting this pain in his behaviour towards staff, but also working in a fallible system that has no easy answers to the limitations within the system. Within this system, the greatest asset is the work of front-line staff. It is they, with the child and family, who bear the brunt of gaps and it is they who face the consequences of gaps and find creative and flexible ways to provide care. The question that arises is: how are front line supported in the emotional cost of proving care in these circumstances?

On a national level, it is understood that part of the crisis in the availability of mental health inpatient beds is due to the difficulty in recruiting and retaining mental health practitioners. The Rapid Review identified a relevant finding: *At a national level consideration needs to be given in relation to how to recruit and retain Children's Mental Health Nurses*. Recognising and responding to the emotional cost of this work will be an important part of the national changes that are needed.

On a local level, it is understood that support is currently in place to provide support to front line practitioners working with Stephen . However, there remains an ongoing need for this support to be in place for the workforce when providing care in a system that faces the pain and distress of children and families. It is imperative that the multi-agency framework recommended in section 6 includes an approach that recognises and supports families and font line practitioners in the care they provide.

10. The Coronavirus Pandemic – a systems dynamic

The terms of reference for this CSPR asked that this review examine the extent the Coronavirus Pandemic limited Ms Wilsons' access and ability to advocate for and support Stephen. This CSPR has found that there was a variable response by organisations to the pandemic and lockdown measures. This variable

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[58] It is understood that this is now being provided.

response was demonstrated by the different hospitals where Stephen has been resident for the past 2 years commencing at the 1st inpatient unit where he was admitted in June 2020.

At this time, a full national lockdown/full restrictions were in place but were in the process of easing. At this unit Ms Wilson was able to advocate for Stephen and was able to see Stephen. In October, concerns that full restrictions were imminent (that may lead to Ms Wilson finding it difficult to have contact with Stephen) influenced the decision to discharge Stephen earlier than planned. In November, Stephen was admitted to a general hospital, full national restrictions were in place. Staff recognised the vital importance of Ms Wilson having contact with Stephen - risk sensible decision making led to Ms Wilson having full access to the ward. In December, Stephen was transferred to the 2nd inpatient unit. Full restrictions were still in place on admission - this eased to a 3-tier system shortly after admission. Ms Wilson was not permitted to see Stephen over this period. At the end of the month, Stephen was admitted to the 2nd general hospital. The 3rd national lockdown/full restrictions were pending at this time and were enforced at the start of January 2021 when Stephen was admitted to the 3rd inpatient unit. At both hospitals, Stephen's need to have contact with his mother was fully recognised and Ms Wilson had full access to support her son and advocate on his behalf.

Panel members have said*: We were all learning as we went along.* This is understood and accepted. Government guidance was in place in relation visiting during the lockdown /restrictions and it is clear that there was a variable response to this guidance with some organisations taking risk sensible decisions that allowed for discretion and flexibility in how this guidance was implemented. The reason for this is unclear – although it seems this may be influenced by the leadership and culture within organisations. Those most flexible were in house services provided by NHSE - the 2nd inpatient unit was a commissioned service. This suggests that when learning from the pandemic, NHSE should consider how their commissioned services can be better supported to align with this leadership and culture to make risk sensible decisions on behalf of a child and family.

11. Conclusion

The complexity of Stephen's needs is reflected in the complexity of the muti-agency landscape of service provision. Unsurprisingly, this CSPR has found that there are no easy answers and no quick fixes to address the issues that have been identified. At the heart of this CSPR is Stephen and his family – a child and family whose story is a salutary narrative not of complexity but of an ordinary family striving for an ordinary life with dreams and aspirations for the future. Sadly, these dreams are currently out of view. Parents, alongside multi-agency practitioners and services, are struggling to do what they can to improve Stephen's current lived experiences and to nurture a vision of a better future.

This CSPR has identified that local changes are needed, CSCP are committed to make the necessary local changes to better support children and families and front-line staff. However, it is clear that national changes are needed, and this is well understood - there is a pressing need for the pace of change to be in time for children and families.