



Waltham Forest Safeguarding Children Board

Child Safeguarding Practice Review - Khalsa November 2020

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1. Introduction and reason for the review.

Under Working Together 2018, The Local Safeguarding Partnership for Waltham Forest Children Safeguarding Board agreed to the recommendation from the One Panel (multi-agency forum that takes referrals for local or statutory reviews and makes recommendations against the statutory criteria) to undertake a Child Safeguarding Practice Review in respect of Khalsa who sadly died aged 14 years old, in October 2019.

This Child Safeguarding Practice Review concerns the unexpected death of a 14-year-old boy, who we are calling Khalsa, and the services provided to Khalsa and his father during the 24 months preceding his death. Khalsa had a diagnosis of acute asthma and had been in receipt of medical services for the treatment of this since he was approximately 3-4 years old. The cause of death was recorded as bronchial asthma, a natural death caused by an acute asthmatic event.

It is imperative that Khalsa and his family have their identity protected, so while the review has looked in detail at his circumstances this report does not include these details.

Khalsa had been a resident of Waltham Forest with his father and 3 older, adult siblings. They resided in a 3-bedroom property which the father described as cramped for the size of their family and with issues such as damp which he had been trying to resolve with the local authority housing department.

Khalsa was being raised by his father following the sudden death of his mother when he was 7 years old. The death of his mother was understandably devastating for the family and they struggled to adapt to the changes of their world. Khalsa attended a local secondary school and there were no concerns about his educational attainment or presentation.

Khalsa was raised within the Sikh faith and this was important to him and his family. Khalsa was described by those who knew him as a kind and helpful young person who sought to do the right thing and was loyal to those who knew him.

Khalsa often presented as “well” which meant that some people involved with him may have underestimated the severity of his illness. This ‘over optimism of wellness’

created a contradiction for professionals about the possible risks to Khalsa within the safeguarding context.

Khalsa's asthma was said to be "managed" We know from the information presented as part of the review that he also experienced episodes of significant incidents which resulted in emergency medical services being called on 3 occasions prior to his death. On the 3rd occasion ambulance and hospital staff were unable to revive him and he was pronounced dead on the 12th October 2019 with the cause of death given as respiratory arrest due to asthma

Family Involvement Khalsa's father was approached and agreed to contribute to this review. Khalsa's father met with the lead reviewer and a review team member connected to the school. His contributions have been included in this report and we are grateful for this. The pseudonym Khalsa was chosen by his father, as a recognition of his child, who he was and his strong commitment to his Sikh faith.

2. Methodology and agencies involved.

This review has been carried out in a way that reflects the principles of a systems-based approach.

The review seeks to understand why things happened in the way that they did. Broadly this means using this case as a 'window on the system', asking the question: ***What does Khalsa's experience tell us about how systems work?*** This systems approach focuses on multi-agency professional practice. The goal is to move beyond the case specifics of the particular case and ask what happened and why, to identify the underlying issues that are influencing practice more generally. The aim is to look for areas that relate to systemic issues, which will lead to changes in practice. The review is not about blame. The focus of the review is very much on learning and improving practice for the future.

Data was gathered from a variety of sources, including the review of existing documentation alongside data provided by front line practitioners and their managers and senior managers in the review team. Additional advice and reflections were sought from a specialist asthma health professional.

The final report has been authored by Gill Nash and Suzanne Elwick (Head of Strategic Partnerships) who are employed by the London Borough of Waltham Forest and Dave Peplow (Independent Scrutineer for the WFSCB) who is independent of the partnership. Significant contributions were provided by Liz Royale, Designated Nurse for Children at Newham CCG. The Senior Responsible Officer for the partnership overseeing the review was Ghislaine Stephenson, Associate Director of Nursing for Children, Barts Health Trust.

The review period is from November 2017 to October 2019, covering the two-year period preceding Khalsa's death.

The review group was made up of senior managers from all those agencies involved with Khalsa and his family in the 24 months before his death. The review group met

with the lead reviewer to consider emerging issues and took part in a workshop with frontline practitioners who knew Khalsa and his family. The review team appreciated the professional, open and honest way all concerned conducted themselves throughout the process.

The agencies involved were:

London Borough of Waltham Forest

- London Borough of Waltham Forest Safeguarding Team
- London Borough of Waltham Forest Early Help Team
- London Borough of Waltham Forest Housing Department

Health

- Barts Heath Trust – Royal London Hospital
- Waltham Forest CCG
- GP
- Homerton University Hospital NHS Foundation Trust – Named Nurse and Asthma Nurse.
- North Middlesex University Hospital Trust
- North East London Foundation Trust NELFT – Asthma Nurse/school nurse

London Metropolitan Police Service

- Specialist Case Review Group

3. Findings and learning points

Asthma

Asthma is the most common long-term medical condition in children. It is an inflammatory condition that affects the airways. The usual symptoms include wheeze, difficulty in breathing, chest tightness and coughing, particularly at night or in the early hours. Its severity varies from mild, moderate to severe and can cause physical and psychological distress affecting quality of life. It cannot be cured but, with appropriate management, quality of life can be improved.

(Healthy London Partnership, August 2020)

Safeguarding pathways.

There was much discussion during the review with both the review team and practitioners about pathways. We explored professionals' recognition of appropriate safeguarding pathways, with specific reference to how asthma is viewed and how this impacted on professional's confidence to manage the concern. The concerns in this case were health specific. Khalsa was otherwise well cared for and his overall needs were met. When concerns are raised about parental capacity in relation to a singular issue the overwhelming positivity of other factors can minimise the real risk

of the health concerns. The following findings impacted on how the issues in this case were managed but we highlighted a definitive need for all professionals within the safeguarding partnerships to understand the different local health safeguarding pathways as this was not known to all. This would enable the relevant agencies to understand and access the expertise of the professional's networks, specifically access to those with medical expertise.

Summary of Findings

Finding 1	Systems communication between multiple universal and acute medical services and Trusts was not conducive to allowing practitioners to understand and contribute to the risk discussion. At times the right people did not have the right information at the right time.
Finding 2	There is a need to create systems that enable young people to have a voice to influence and participate in their own health plans – specifically when young peoples' competence to do this is overridden by parental influence.
Finding 3	The perception of asthma as not being potentially life threatening can impact on how some professionals engage in professional curiosity, specifically in the context of safeguarding.

Finding One

Finding 1	Systems communication between universal and acute medical services was not conducive to allowing practitioners to understand and contribute to the risk discussion. At times the right people did not have the right information at the right time.
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How are these issues evident in this case?

Khalsa had acute asthma for which his overall treatment was led by a named hospital consultant. Acute asthma for Khalsa meant that he would experience sudden onset of an exacerbation of his asthma that were life threatening on several occasions (and ultimately lead to his death). These sudden incidents meant that Khalsa also received services from hospital emergency departments in conjunction with his usual interactions with universal services such as school nursing, general practitioner and a specialist asthma nurse. Dependent upon the information or presentation of Khalsa at the time, they had different understandings of the risks that Khalsa was exposed to by his asthma.

In general, Khalsa was presenting as well and managing his asthma to the point that some professionals perceived his asthma to be less of an issue as it appeared to be under control. Other professionals saw different information such as presentation via ambulance at the emergency department following a serious asthma incident which led them to a different assessment of risk. The differing professionals were not in possession of the same information at the same time, altering their risk assessments at different points.

Khalsa's medical practice had increasing concerns about the management of Khalsa's asthma and made two referrals to social care in 2018. They were concerned about the repeated requests for reliever inhalers made by Khalsa's father and what this meant for Khalsa's management of his asthma and his father's understanding of how to support Khalsa with managing his asthma.

Following an assessment, a decision was made that Khalsa's situation should be presented to a child protection conference, the lead consultant was unable to attend and was not in possession of all of the information known to professionals. Whilst some health practitioners attended the conference, Khalsa had attended different emergency departments in different Trust areas so they were not in possession of all the information. This meant that professionals were partially reliant on self-reporting from Khalsa and his parent. This led to a different understanding of risk. Some professionals who attended the child protection conference felt that there was a 'confusion' about what the risks were for Khalsa and how this risk was managed by his parent. The decision made at the Child Protection Conference was that Khalsa would be made the subject of a Child in Need plan.

Some professionals expressed concerns that Khalsa's asthma was not being managed properly and there was an over reliance of salbutamol inhalers with 40 being prescribed in a 12-month period as opposed to a usual prescription being one inhaler every one to two months. Khalsa's asthma would result in episodic periods of hospitalisation including being admitted to the Intensive Care Unit on 2 occasions prior to his death. Some professionals expressed concerns that they had tried to advise father of the concerns about over reliance on the salbutamol inhalers, and how this raised concerns about Khalsa's asthma management. They reported that when challenged about his approach to Khalsa's asthma management father would seek advice from another health provider.

Khalsa's lead asthma consultant said that he was not aware of these concerns presenting in universal services, and this impacted on his assessment contributions to the child protection conference, being that Khalsa's asthma was well managed and possible allergy related and was likely to improve.

Whilst the communication between universal health services was relaying the information, they knew between themselves, information from acute and specialist health services was not known and the pathways between them were not effective.

On the 20/11/18 Khalsa was taken to see his lead asthma consultant by his father. The notes of that session state that he had no hospital admissions since the last review. The following information was not shared with the lead consultant in time for the asthma review:

- **01/07/2018** – Khalsa is admitted to the Hospital via ambulance due to acute exacerbation of his asthma
- **23/07/2018** -Khalsa attends the emergency department due to an asthma incident.
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- **31/07/2018** -Barts Health is informed via letter of Khalsa's admission to Hospital.
- **13/08/2018** The school nursing team receives information via letter that Khalsa attended the emergency department on 23/07/2018.

There is a reliance on parental self-reporting to support the ethos of people as experts of their own health. Whilst this ethos is important there is a difficult balance to strike and there is a need for professionals to be curious to consider if there are questions around risk management.

The communication systems between universal and acute and specialist health services did not support the lead consultant to explore what risks were being presented for Khalsa by his current management of his asthma.

Khalsa's father reported to the review that he believed that the health professionals had systems that would tell them all the health information and attendances for Khalsa. When health professionals did not raise it, he believed that they did not consider there to be risk. He did not provide the health professionals with these parts of Khalsa's medical history as he was concerned that to bring attention to it would raise concerns about his care of Khalsa and Father was concerned that Khalsa would be removed from his care.

The lead consultant shared with the review that had he known this other information he would have presented a very different contribution to the risk discussion at the child protection conference.

The delays in information being provided to relevant professionals enabled minimisation of risk considering Khalsa's presentation at the time. As his acute asthma incidents were episodic, an over optimism of wellness enables a minimisation of how at risk Khalsa's asthma made him.

Does this happen in other cases?

Professionals told us that this is a continuing problem and that the outdated systems within the health service do not support the wider conversation for professionals when supporting and addressing health concerns with children and their families. Whilst this has been addressed in universal services, the acute and specialist systems have not managed to find a way to share this information in a timely way.

Why does it matter?

An over reliance on self-reporting means that professionals can become limited in how they view the child's world and act in a responsive way. It places an emphasis on parents, carers and young people to lead the discussion and allows avoidance of conversations that some people may not want to have. It limits professionals' abilities

to engage their responsibilities for wider safeguarding and therefore places some children at risk of harm. Having communication systems that ensure information is relayed to the right people at the right time would help to reduce this risk.

Questions for the Waltham Forest Children’s Safeguarding Partnership

What changes need to take place between multiple universal and acute hospital trusts to ensure robust and timely information sharing between them?

Finding two

Finding 2	There is a need to create systems that enable young people to have a voice to influence and participate in their own health plans – specifically when young peoples’ competence to do this is overridden by parental influence.
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How are the issues evident in this case?

Khalsa met with a range of professionals, many of whom; such as his education professionals, some health professionals and his social workers, tried to encourage Khalsa to share his views and influence his own care plan. Khalsa often echoed the views of his father and as such his voice could not be loudly or consistently heard in the reflections of the review.

There were some representations of good practice in the provision of some of the support offered to Khalsa but there was not a consistency in the approach. These incidents of good practice were dependent on the skills and experience of the practitioner. Practitioners in the review process shared many of the positive approaches that they tried in this case, and which have been successful in many others, but all agreed that the challenge was presented by Khalsa’s carer as an expert in his child’s health and well-being. As there was not a standardised approach or framework to the work, they attempted to undertake with Khalsa professionals experienced feeling disempowered with being able to move it forward.

Khalsa’s father informed the review that Khalsa was a shy young person with some people in positions of “power” and so it was easier for him to repeat his father’s views than have his confidence developed to air his own.

There have been many developments in how the professional networks have developed practice to support children and young people to be empowered with their own health. For example, children with diabetes are taught very early on to recognise changes in their bodies and to administer insulin.

Does this happen in other cases?

Practitioners described many positive examples of ways in which children and young people were encouraged to have influence over their own health care plans in the context of asthma. This was not consistent and was practitioner dependent. They also informed the review that as this practice was not standardised it deskilled them when presented with parents and carers who were more vocal of their own perspectives of health management. This enables young peoples' involvement to be placed secondary to the maintenance of parental relationships with practitioners.

The Healthy London Partnership¹ in August 2020, recognised the vast variations of practice and responses to children with asthma. The report states its ambition for children and young people with asthma is that they are enabled to

"..... manage their own asthma by having access to a personalised, interactive, evidence-based asthma management plan that they understand and that is linked to their medical record" (pg. 6)

Practitioners confirmed that there was inconsistency across London and nationally with how young people are engaged in their health care plans.

Why does it matter?

Asthma is one of the most common medical conditions for children. Our current data shows that there are 16,268 residents of Waltham Forest with a diagnosis of asthma. Of these 1851 are young people aged 10-18 years old. Approximately 10 people per year die in Waltham Forest every year from Asthma which is above the national benchmark. In August 2019, Asthma UK reported that there had been a 17% increase in London of deaths from asthma.

Engaging children and young people in their asthma health care plans enables there to be equal recognition of the severity of asthma for children's health outcomes, on a par with other conditions such as epilepsy and diabetes. Engaging young people early in recognition and management of their health conditions enables them to develop the competency for long term management of their conditions.

Questions for the Waltham Forest Children's Safeguarding Partnership

How confident is the partnership that it meets the recommended London Asthma Standards for Children as detailed in the report from the Healthy London Partnership?

Finding 3

¹ <https://www.healthylondon.org/wp-content/uploads/2017/11/London-asthma-standards-for-children-and-young-people.pdf>

Finding 3	The perception of asthma as not being potentially life threatening can impact on how some professionals engage in professional curiosity, specifically in the context of safeguarding.
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How were the issues evident in this case?

Khalsa's acute asthma had a devastating impact on him, resulting in his death in October 2019. In the 24 months preceding his death he was admitted to hospital due to asthma related concerns on the following occasions;

- 03/03/18 – North Middlesex Hospital;
- 01/07/18 Homerton Hospital and
- 12/01/19 North Middlesex Hospital.

At all other times, there were mild symptom presentation but otherwise, Khalsa did not present with any other indicators that he was unwell.

Father states that Khalsa's asthma difficulties were more prevalent when he was at home, and this is evidenced by his emergency admissions from home. This meant that many of the practitioners involved with Khalsa did not see the impact that the acute asthma exacerbations had.

There were additional challenges brought by a pattern of cancelling and rescheduling appointments by Khalsa's father, which meant there were periods of time when Khalsa was not brought to appointments. There is not currently a system that highlights cancelled or rescheduled appointments to signal to health professionals of a need for additional engagement to explore why this is happening.

Concerns were raised by the General Practitioners that the father was requesting excessive amounts of the salbutamol inhalers, indicating concerns about how Khalsa's asthma was being managed, but in the community the impact of this was not being seen consistently by professionals engaged with the family as Khalsa presented as 'well'. Coupled with perceptions of asthma as a manageable condition, this inconsistency in terms of the concerns led to differing opinions on the risk presented by asthma to Khalsa and the impact of the concerns raised about how this was being acknowledged and managed. The people who could guide this understanding were not in possession of the other concerns and as such this impacted on the advice provided to universal services.

Does this happen in other cases?

Asthma is a common condition, and perhaps its commonality leads to complacency about its impact on people's lives. In 2018, 1400 people died from an asthma related condition. Despite this, Asthma is not given the same deference as other conditions such as epilepsy and diabetes. There is a greater understanding of the need to manage these other conditions and the significant health risks associated with them. The specific discipline of the professionals involved, and the information they were

provided impacts on how they view the risks and therefore the risk management of asthma.

Why does it matter?

Asthma UK² published the National Asthma Survey in 2019 showing that 8 in 10 people still do not have well controlled asthma resulting in 75,000 emergency admissions for asthma. In Waltham Forest, 16, 268 of residents' experience asthma with a mortality rate of 10 deaths per year. Specific data of how many of these are children is not recorded but does show that we need to increase awareness and responses to how this is managed in the borough. Hospital admissions for Waltham Forest show that 80 residents aged 10 to 18 years old are admitted to hospital every year which is above the national benchmark and higher than expected based on prevalence (Waltham Forest Public Health data 2020). This demonstrates that there is a need in Waltham Forest for consistent understanding and response to adolescents with asthma in Waltham Forest

Questions for the Waltham Forest Children's Safeguarding Partnership

How will the partnership increase awareness of asthma and its management across agencies and communities in Waltham Forest?

² <https://www.asthma.org.uk/58a0ecb9/globalassets/campaigns/publications/The-Great-Asthma-Divide.pdf>