Safeguarding Adult Review 'Ella'

Commissioned by Kingston Safeguarding Adult Board

EXECUTIVE SUMMARY

Succinct summary of the case

Ella sadly died at the age of 23 years from heart failure related to a fatty liver. Safeguarding adult concerns had been expressed by several organisations, as, supported by her mother, Ella sought to engage with many private and NHS services to manage a range of reported health conditions that included having a brain tumour. The safeguarding concerns included whether there was an element of fabricated or induced illness (FII) in Ella's presentation. A police investigation had also been initiated due to concerns about fraud linked to a charity set up and run by Ella and her mother to raise money for children with terminal illnesses, including Ella. Ella's post-mortem examination revealed no brain tumour. The coroner stated there was no evidence that she had any physical illness.

Methodology and focus research questions

The SAB decided to use SCIE's tried and tested Learning Together model for reviews to conduct this SAR (Fish, Munro & Bairstow 2010). Learning Together provides the analytic tools to support both rigour and transparency to the analysis of practice in the case and identification of systems learning.

The use of research questions in a Learning Together systems review is equivalent to Terms of Reference, but focuses on the generalizable systems learning that is sought. The research questions identify the key lines of enquiry that the SAB want the review to pursue and are framed in such a way that make them applicable to casework more generally, as is the nature of systems Findings. The research questions provide a systemic focus for the review, seeking generalizable learning from the single case. The research question agreed for this SAR is as follows.

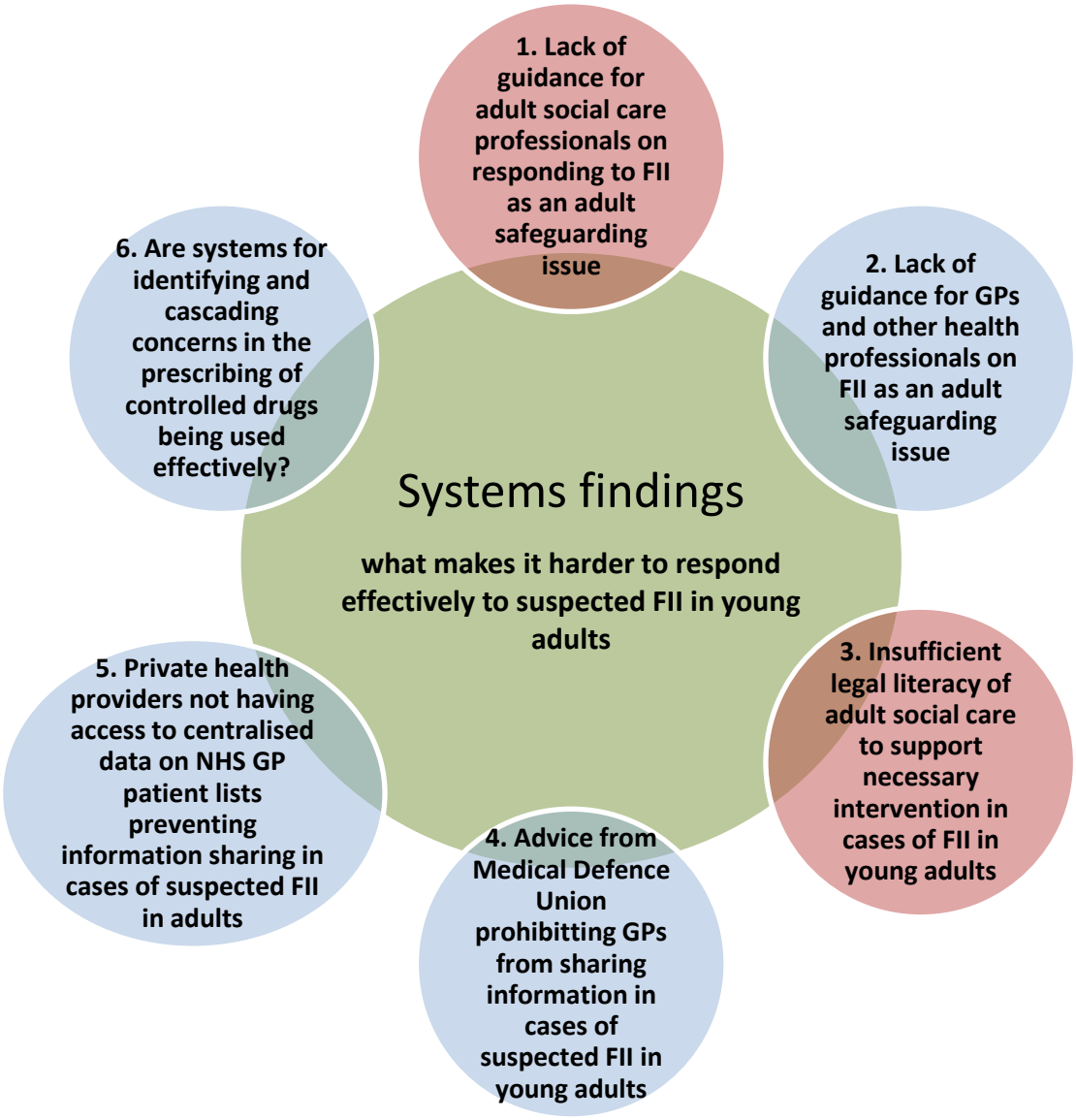
What can this case tell us about what's helping and hindering professionals across agencies from:

- recognising potential FII in young adults, raising concerns and progressing them effectively?

Despite there being no formal diagnosis of FII in this case, the presentation and coroner's conclusion lead all involved to think it was likely to have been FII.

In what ways does this case provide a useful window on our system?

Six systems findings have been prioritised from Ella's case for the SAB to consider. These are:



Findings 1 and 3 relate to adult social care and highlight a lack of guidance for safeguarding teams, and insufficient legal literacy relevant to FII in young adults respectively. Findings 2, 4, 5 and 6 all relate to issues affecting professionals in the health 'economy'.

Coded systems findings

A summary of each systems findings is presented in the table below, capturing what the systems issue is and why it matters. Each finding is coded using the four-part category scheme developed by Sheila Fish (SCIE) to enable real time collation and comparison of learning from reviews.

	Finding			
1.	FINDING 1: **FII GUIDANCE FOR ADULT SAFEGUARDING** There is a total lack of safeguarding guidance and training related to Fabricated and Induced Illness in young adults, for professionals with statutory adult safeguarding responsibilities. This increases the chances that even when concerns about FII in a young adult have been identified by another agency and a safeguarding referral has been made to the adult social care team, adult social workers will not understand the nature of concerns being shared or what their Section 42 Enquiry needs to explore.			
	What circumstance or care and support needs does the finding relevant to?	Which professionals does it affect?	Does it relate to a particular kind / area of work?	What kind of systems issue is it?
	Suspected FII in young adult	Adult social care safeguarding	s.42 safeguarding inquiries	Management system issue - guidance
2	FINDING 2: **FII GUIDANCE FOR HEALTH PROFESSIONALS** There is a lack of safeguarding guidance and training related to Fabricated and Induced Illness in young adults, for hospital and GP based health professionals. This means that any good practice in information sharing across hospitals and across NHS/private divisions is likely to happen without consistent involvement of designated safeguarding leads, or reliable referrals into adult safeguarding teams.			
	What circumstance or care and support needs does the finding relevant to?	Which professionals does it affect?	Does it relate to a particular kind / area of work?	What kind of systems issue is it?
	Suspected FII in young adult	Hospital and GP based health professionals- designated safeguarding leads and/or adult	Information sharing	Management system issue - guidance

		safeguarding teams		
3	FINDING 3: **FII AND LEGAL LITERACY** Where professionals have concerns about the risk of harm related to ?FII by a young adult, the default legal framework considered tends to be the Mental Capacity Act, which is then hampered by the lack of a diagnosis of FII. This detracts from consideration of whether the young adult was a victim of FII by proxy, by their parents/carers in childhood, and the legacy impact of this coercion and control and/or any related medication dependencies, which might open the possibility of other legal basis for action without requiring any diagnosis. Without considering the impact of non-recent child abuse on an adult's capacity to make medical decisions, increases the risk of people being doubly victimised			
	What circumstance or care and support needs does the finding relevant to?	Which professionals does it affect?	Does it relate to a particular kind / area of work?	What kind of systems issue is it?
	Suspected FII in young adult	Adult social care safeguarding	Legal literacy / frameworks	Management system issue – expertise
4	FINDING 4. **FII AND MEDICAL DEFENCE UNION ADVICE ABOUT INFORMATION SHARING** When an adult says they no longer want to be under the care of a particular GP, GPs are required to deregister the patient from their list/practice. The view of the Medical Defence Union is that from this point the GP no longer has a right to access or share information about the person. The result is a set up that actively enables Fabricated and Induced Illness by making information sharing among professionals impossible when patients attempt to avoid challenge and safeguarding interventions by "GP hopping".			
	What circumstance or care and support needs does the finding relevant to?	Which professionals does it affect?	Does it relate to a particular kind / area of work?	What kind of systems issue is it?
	Suspected FII in young adult	GPs and health consultants	Data access and information sharing	Management system issue – MDU legal advice
5.	FINDING 5: **FII AND BARRIERS TO THE PRIVATE HEALTH SECTOR INFORMATION SHARING** GPs working in the private sector are currently unable to access any centralised data about patients, leaving them reliant on the patient to voluntarily share details of their last NHS GP in order that			

	medical records can be shared. In contexts of Fabricated and Induced Illness in children or young adults, and/or medication dependencies, this reduces the chances of effective information sharing and collaboration across GPs to build an accurate picture of the history and circumstances, and so facilitates attempts by the patients to avoid challenge and safeguarding interventions by "GP hopping".			
	What circumstance or care and support needs does the finding relevant to?	Which professionals does it affect?	Does it relate to a particular kind / area of work?	What kind of systems issue is it?
	Suspected FII in young adult	Private health sector professionals	Data access and information sharing	Management system issue – national NHS data systems
6	FINDING 6: **IDENTIFYING AND REPORTING CONTROLLED DRUGS INCIDENTS** Are systems for identifying and cascading concerns in the prescribing of controlled drugs being used effectively? If not, it makes it easier for opiates to be fraudulently obtained and used, with potentially life-threatening effects.			
	What circumstance or care and support needs does the finding relevant to?	Which professionals does it affect?	Does it relate to a particular kind / area of work?	What kind of systems issue is it?
	Suspected FII in young adult	Health professionals	Identifying and reporting controlled drugs incidents	? unclear at the moment

Questions to help considerations of how to address systems issues identified

Below each presents a summary of the systemic risk linked to each systems findings, followed by a series of questions. These are posed to aid discussion about how best to tackle the systems issues identified in this SAR.

FINDING 1 – FII GUIDANCE IN ADULTS FOR ADULT SAFEGUARDING PROFESSIONALS

FINDING 1: There is a total lack of safeguarding guidance and training related to Fabricated and Induced Illness in young adults, for professionals with statutory adult safeguarding responsibilities. This increases the chances that even when concerns about FII in a young adult have been identified by another agency and a safeguarding referral has been made to the adult social care team, adult social workers will not understand the nature of concerns being shared or what their Section 42 Enquiry needs to explore. (Management system issue)

SUMMARY OF SYSTEMIC RISKS

Safeguarding adults is a complex field of expertise due to the legal literacy required, the range of care and support needs, and kinds of abuse, neglect and self-neglect. A range of guidance exists to support adult social care to be adequately evidence-based in their approaches, and to support efficiency and effectiveness in practice responses. This finding highlights the gap in such guidance as regards FII in young adults, for adult safeguarding processionals. Without this, we can expect that they will proceed as novices and people will not be protected when it is necessary.

QUESTIONS FOR THE SAB TO CONSIDER:

- DHSC has commissioned SCIE to develop guidance to address this finding. How might the SAB best support this process?
- What can the SAB do locally to raise knowledge of the evidence-base about FII in young adults for adult safeguarding professionals locally.
- How would the SAB know if things had improved?

FINDING 2 – FII IN YOUNG ADULTS GUIDANCE FOR HEALTH PROFESSIONALS

FINDING 2: **There is a lack of safeguarding guidance and training related to Fabricated and Induced Illness in young adults, for hospital and GP based health professionals. This means that any good practice in information sharing across hospitals and across NHS/private divisions is likely to happen without consistent involvement of designated safeguarding leads, or reliable referrals into adult safeguarding teams. (Management system issue)**

SUMMARY OF SYSTEMIC RISKS

Many health professionals will often be the eyes and ears when it comes to identifying concerns about possible FII in adults, as with other kinds of abuse, neglect and self-neglect. Other health professionals will provide specialist expertise in assessment and intervention. However, this finding highlights that training and guidance is only available for the latter, and not for the former, increasing the chances that safeguarding concerns linked to FII in young adults are not recognised or shared when they should be.

QUESTIONS FOR THE SAB TO CONSIDER:

- What are the options for the SAB to raise this finding with NSHE?
- Is there anything that could usefully be done to cultivate expertise locally among health care staff?
- How would the SAB know if things had improved in this area?

FINDING 3 – CONSIDERING DOMESTIC ABUSE LEGISLATION IN RELATION TO CASES INVOLVING FII IN YOUNG ADULTS

FINDING 3: **Where professionals have concerns about the risk of harm related to FII by a young adult, the default legal framework considered tends to be the Mental Capacity Act, which is then hampered by the lack of a diagnosis of FII. This detracts from consideration of whether the young adult was a victim of FII by proxy, by their parents/carers in childhood, and the legacy impact of this coercion and control and any related medication dependencies, which might open the possibility of using the Domestic Abuse Act (2021) without requiring any diagnosis. Without considering the impact of non-recent child abuse on an adult's capacity to make medical decisions, increases the risk of people being doubly victimised. (Management system issue – legal literacy)**

SUMMARY OF SYSTEMIC RISKS

People have complex and multi-faceted lives, wants, and needs. A range of legal frameworks also exist providing the basis for professional intervention in different circumstances. Safe systems require sound legal literacy among professionals as well the analytic dexterity and disposition to consider a range of legal options in different contexts. This finding highlights a professional norm whereby a focus on mental capacity rules out a focus on safeguarding in the particular context of suspected risks

linked to FII on the part of a young adult and/or non-recent and/or contemporary FII by proxy on the part of their mother/parent/carer. The focus of a person being assessed as having capacity to make a decision about their care and treatment needs creates a shorthand for professionals' withdrawal in terms of safeguarding, citing a person's ability/ freedom to take an "unwise decision". In the context of suspected FII or FII by proxy, this runs the risk that a safeguarding response is not considered to assess and manage potentially significant and serious mental health issues, coercion and control dynamics, and risk related to unnecessary health interventions. The opportunity for discussion of the contextual information related to drug-seeking and medical-intervention seeking behaviours and their potential risks is therefore lost in light of the person having been assessed as having capacity, together with routine opportunities for multi-agency discussions and risk assessments.

QUESTIONS FOR THE SAB TO CONSIDER:

- How can the link between mental capacity, supported decision-making, free and informed choices, and safeguarding be strengthened?
- Does the Partnership have a role in garnering cross-agency focus on this issue?
- What mechanisms could be put in place to enable practitioners to see drug-seeking and medical intervention seeking behaviours, in the context of non-recent concerns in childhood of FII by proxy, as a safeguarding issue in the context of domestic abuse and/or self-neglect?
- What are the current forums amongst partner agencies that allow and foster discussions of potential coercive control dynamics between parent and child, linked to FII and FII by proxy, where the adult-child might otherwise be assessed as having capacity? Is there a need to create new/ additional opportunities?
- How would the Safeguarding Board know if practice in this area had improved?

FINDING 4 – FII AND MEDICAL DEFENCE UNION ADVICE ABOUT INFORMATION SHARING

FINDING 4: **When an adult says they no longer want to be under the care of a particular GP, GPs are required to deregister the patient from their list/practice. The view of the Medical Defence Union is that from this point the GP no longer has a right to access or share information about the person. The result is a set up that actively enables Fabricated and Induced Illness by making information sharing among professionals impossible when patients attempt to avoid challenge and safeguarding interventions by "GP hopping". (Management system issue – MDU legal advice)**

SUMMARY OF SYSTEMIC RISKS

Safeguarding adults can mean professionals, in some circumstances, necessarily walk a thin line between infringing on a person's rights and liberties, and wrongly leaving them at risk of significant harm. In this context, it is vital that legal advice is accurate. This finding raises questions about the understanding within the MDU of Fabricated and Induced Illness FII in young adults and the legacy of FII by proxy during childhood, and implications in terms of the safeguarding responsibilities of medical professionals. This increases the risk that advice ends up pitting the professional's safety (from legal challenge) against that of a citizen at risk of serious harm. As we saw in this case, this can put the brakes on vital information sharing and multi-agency assessment and planning, reducing the effectiveness of efforts to prevent fatalities.

QUESTIONS FOR THE SAB TO CONSIDER:

- What are the best options for the Board to escalate this national issue related to MDU advice regarding situations involving strong concerns about FII in young adults?
- How might the Board and partners use your networks to explore whether other GPs have had similar MDU advice?
- Are there options for opening conversations with the MDU regarding how safeguarding adults' responsibilities are factored into their advice?
- How would the SAB know if there had been progress in addressing this finding?

FII AND BARRIERS TO THE PRIVATE HEALTH SECTOR INFORMATION SHARING

FINDING 5: **GPs working in the private sector are currently unable to access any centralised data about patients, leaving them reliant on the patient to voluntarily share details of their last NHS GP in order that medical records can be shared. In contexts of Fabricated and Induced Illness in children or young adults, and/or medication dependencies, this reduces the chances of effective information sharing and collaboration across GPs to build an accurate picture of the history and circumstances, and so facilitates attempts by the patients to avoid challenge and safeguarding interventions by "GP hopping". (Management system issues – information sharing with private health sector)**

SUMMARY OF SYSTEMIC RISKS

NHS GPs are a lynch pin of the wider English health care system. All health information is shared back with a patient's NHS GP as the central repository of their health care history. A safe system would therefore allow all health providers whether private or NHS, access to this information. This finding highlights that this is not the case and private GPs as well as private acute providers do not have access to the available GP data that NHS professionals have. This created heightened risks in cases of fabricated and induced illness, and drug-seeking behaviour, that private health providers act in the dark, unaware of safeguarding concerns, and inadvertently do harm.

QUESTIONS FOR THE SAB TO CONSIDER:

- What options are there for the SAB to escalate this issue with NHSE?
- Is there a role for the SAB to engage with private health providers locally to encourage a consensus on this issue and commitment to requiring NHS GP details are shared on registration?
- How would the SAB know if things had improved in this area?

FINDING 6 – SYSTEMS FOR SHARING INCIDENTS INVOLVING FRAUDULENT EFFORTS TO OBTAIN OPIATES

FINDING 6: **Are systems for identifying and cascading concerns in the prescribing of controlled drugs being used effectively? If not, it makes it easier for opiates to be fraudulently obtained and used, with potentially life-threatening effects. (Professional norms and culture)**

SUMMARY OF SYSTEMIC RISKS

Safe systems have defences and safeguards to flag unwarranted / illegal activity. Across the health economy, one such system is that designed to identify and escalate instances where controlled drugs are fraudulently prescribed or otherwise accessed. However, this case raises questions about how well the role of medication safety officers, and established notification systems and medicine safety networks are working, risking false confidence in the understanding and overview of safety and error in this area. Any weakness in the workings of these defences, increases the chances that people can access drugs successfully without appropriate consultant oversight and decreases the chances that they get help to address their dependencies.

QUESTIONS FOR THE SAB TO CONSIDER:

- Has the SAB every considered systems for identifying and cascading concerns in the prescribing of controlled drugs as a safeguarding issue?
- Is there a role for the SAB to better understand how well systems for identifying and cascading prescribing incidents, are working locally?
- How would the SAB know if there were improvements in this area?