Serious Incident Investigation Report

Secretary of State Case Review into Beth
October 2019

Contents

‘Nothing is more important than children’s welfare. Children who need help and protection deserve high quality and effective support as soon as a need is identified’

(HM Government 2018).

1. Executive Summary

1.1 This report presents the findings of a review into the care and management of Beth, a Looked After Child (LAC), who was 17 when her case came into the public domain.

1.2 This review, commissioned by the Secretary of State (SoS) for the Department of Health and Social Care (DHSC), was led by NHS England (NHSE) who established an Oversight Group (OG) with broad membership to ensure appropriate breadth of knowledge and consideration. It should be noted that the review has been designed to identify required improvements rather than apportion blame.

1.3 Beth is introduced with a pen portrait by her parents identifying a girl who loves laughing. Beth's parents have been her constant support despite the personal cost to them.

1.4 A high-level summary chronology of Beth's experiences provided a degree of information and context to enable understanding and interpretation of the findings.

1.5 The chronology is presented in three sections:

- 3 – 11 years which sees a lack of coordinated multi-agency working despite evidence of behaviour that challenged, from a very early age.
- 12 – 15 years which sees Beth's first admission into in-patient health care where she learns to self-harm and tie ligatures.
- 16 – 18 years which describes her time at St Andrew's Healthcare (STAH), where Beth learned to equate seclusion with safety.

1.6 The review findings are presented utilising themes that the OG determined best illustrate Beth's experiences as well as system responsibilities. These themes are:

- **Parents as partners**: Beth's parents were never seen as partners in the care of their daughter and over time have moved to a combative position as a consequence of lack of involvement, acknowledgement and voice.

- **Model of Care & Pathway to institutionalised Care:** Measured against the findings of the Lenehan Review (2017), the lack of diagnosis for Beth, meaningful intervention and management set Beth on a pathway that was foreseen as poor and ended inevitably in institutionalised care.

- **Hospital environment:** The physical environment coupled with the ethos of care at STAH are considered here.

  The physical environment for a young autistic girl was inappropriate and lacked adjustments to her needs. This led to a cycle of challenging behaviour being met with increasingly restrictive practices. The ethos of care meaning that there was a failure to recognise the communication of unmet needs expressed by such behaviours and furthermore normalised profound restrictive practices.

- **Staffing:** The staff delivering the care for Beth at STAH are considered here. Issues are identified in relation to numbers of staff, the skill mix of staff, supervision, training and access to information and support.

- **Safeguarding:** With the exception of the review of safeguarding allegations made against specific individuals, safeguarding issues have not been adequately considered throughout Beth's life in care. There is too narrow a focus for safeguarding leading to considerations of Beth's welfare and development not being recognised as safeguarding issues.

- **Restrictive Practices:** Beth has been subject to restrictive practices from a very early age. In relation to the use of seclusion and Long-Term Segregation (LTS), during Beth's time at STAH there is concern that the legitimisation of such restrictions in the Code of Practice, with limited safeguards and scrutiny has facilitated prolonged use without external scrutiny. Psychological harm and Beth's human rights are inadequately considered.

- **Legal & Regulatory framework:** The regulatory responsibilities of the Care Quality Commission (CQC) are considered here and identifies there has been a lack of follow up of actions from requirement notices and regulatory breaches; a lack of escalation to NHSE of serious concerns and a recognition that there has been inadequate input from carers into regulatory visits.

  Walsall Local Authority (LA) who had corporate parental responsibility for Beth, found that delivering their oversight responsibilities had been challenging due to poor cross agency working, in particular with NHSE (Midlands and East Specialised Commissioners); contradictory medical opinions and advice and their interpretation of their ability to effectively challenge STAH due to Beth's detained status under the Mental Health Act (MHA).

  It is clear that explicit assessment of Beth's human rights is not undertaken by stakeholders and whilst there is a belief that there is implicit consideration and assessment, this is not evidenced.

  The current paradigm is one of risk management in dealing with the risk of Beth's behaviour to herself and others. It is considered that this needs underpinning with an explicit assessment of human rights to support improved care planning.

- **Management of Care & Commissioning Oversight**: During Beth's admission to STAH there is much activity in relation to commissioning oversight but little meaningful action as a consequence of this activity. In a similar way there is significant documentary evidence of care planning for Beth but little evidence of its actual use in the delivery of her care.

  There is a lack of follow up of urgent actions identified as part of formal reviews of Beth's care and therefore little or no impact.

1.7 An addition to the Terms of Reference was made, at the request of Beth's father, to review the failed transfer of Beth from STAH to a community provider. It is identified that this transfer was rushed; contrary to clinical advice; that not all parties were willing to work together to undertake all required actions for the transition to be successful – most importantly STAH failed to support Beth to spend increasing amounts of time out of seclusion. All commissioners considered the balance of risks in relation to speed of transfer against the ongoing potential for damage to Beth by continuation of this inappropriate placement. On balance the decision was to support transfer. However, Beth became rapidly overwhelmed by her new environment and activities on transfer to the community provider.

1.8 A comprehensive list of improvements required to support children like Beth are identified utilising the themes above and are presented. These are numerous and therefore to ensure the most urgent and transformatory improvements are not lost, these are identified as the Headline Improvements and described in the next section. The headlines are as follows:

Figure 1: Headline Improvements: Children & Young People with Autism

• **Early Integrated working across Health, Social Care & Education with a statutory requirement to deliver a jointly owned personalised plan of care built around presenting needs**
• **Co-design with the young person and parents, personalised crisis response plans, that are owned by all stakeholders and can be enacted at any time when required**
• **Develop national guidance/policy to ensure that seclusion or segregation is only utilised for children and young people as a last resort and is subject to stringent review and oversight**
• **A national review of the workforce and training plan for staff across health, education and social care to establish new roles and base competencies of skills and knowledge that will support children and young people with autism**
• **Introduction of a mandatory requirement for the assessment of human rights aligned to a formalised framework for providers and commissioners when a patient is subject to restrictive interventions, including delayed discharge.**
• **Strategic planning and stimulation of market provision that will enable providers (including new entrants/third sector) to develop community provision at scale which will support young people with autism who require bespoke living arrangements**
• **Parents as partners**
• **Hospital environments adapted for children & young people with autism**
• **Robust escalation processes including a system navigator (keyworker) to co-ordinate those cases of significant concern**
• **Ensuring the voice of the young person is heard, including strengthening the role and involvement of advocates**

1.9 At the heart of Beth’s case is the lack of appropriate home-like community provision, with skilled staff to support her to live a fuller life. In the absence of such provision, children like Beth are hospitalised and LA or NHS Commissioners genuinely struggle to find alternatives that can meet their needs.

1.10 The OG has considered Beth’s case in detail and found a system that requires significant change and in fact a paradigm shift in terms of approach. However, whilst the impact of the current system on Beth is clearly articulated and hard to accept, there is nothing new in this report, in that such findings have been previously identified across a range of other reports and reviews. The headline improvements have been identified to fundamentally change the system rather than deliver a further review.

2. Headline Improvements

2.1 The review has identified areas where improvements are required in the system to prevent other children and young people following the same trajectory as Beth. To focus attention around the learning from the review, the OG has extracted a series of headline improvements. The 10 headline improvement areas are identified below.

Figure 2: Headline Improvements: Children & Young People with Autism

1. **Early Integrated working across Health, Social Care & Education with a statutory requirement to deliver a jointly owned personalised plan of care built around presenting needs**

Numerous reports have identified that early intervention is required to prevent the pathway to institutionalised care. Lenehan (2017) identified the model of care that would be required. This is dependent upon joint planning across health, education and social care and experience indicates that this needs to be a statutory requirement for these agencies rather than the existing good practice guidance.

2. **Co-design with the young person and parents, personalised crisis response plans, that are owned by all stakeholders and can be enacted at any time when required**

Where there is potential for crisis, children and young people should be identified on the regional dynamic support register. There is evidence that when the support of a child is in crisis a containment response is initiated by the responsible authority which may then lead to placement breakdown and seeking of a further form of containment through the police and /or hospital. Personalised plans will be in place to ensure that triggers, warning signs of escalating behaviour and responses are known in advance of any such situation arising. There needs to be additional planning for a “worst case scenario” that delivers a response to significant crisis to ensure that hospital admission for ‘containment’ is not the default option. Any plan which refers to calling the police in emergencies should lead to automatic consideration with the police force.

3. **Develop national guidance/policy to ensure that seclusion or segregation is only utilised for children and young people as a last resort and is subject to stringent review and oversight**

There is evidence that admission to inappropriate physical environments initiates a cycle of behaviour that challenges, resulting in increasingly restrictive practices including seclusion. In turn children can learn to equate seclusion with safety, thus, limiting their ability to reintegrate. The use of seclusion for children and young people with autism should be an exceptional event, subject to individual review for every use. A worldwide review will ensure we can describe best practice in the use of seclusion and LTS in hospital for all children and young people through national policy. A review of seclusion in the community should also be undertaken to ensure such packages of care are therapeutic and purposeful.

4. A national review of the workforce and training plan for staff across health, education and social care to establish new roles and base competencies of skills and knowledge that will support children and young people with autism

There is evidence that the workforce supporting children and people with autism are often inadequately trained, supported and supervised. Therefore this plan is to ensure the delivery of developmental, physical, psychological and educational goals with a view to establishing a skilled workforce; to ensure that the workforce receives good supervision and is knowledgeable in relation to behaviour that challenges as a means of communicating distress and is able to reflect on their own emotional responses to these challenges; new roles are identified and developed that will work across health, social care and education to ensure people with autism can lead a fulfilling life.

5. Introduction of a mandatory requirement for the assessment of human rights aligned to a formalised framework for providers and commissioners when a patient is subject to restrictive interventions, including delayed discharge

There is evidence that formal assessments of the implications of the human rights act in relation to the care and management of children and young people with autism are not undertaken. An organisation with expertise in human rights in the context of health and social care should be commissioned to assist in developing the framework and provide training for all registered professionals and commissioning staff. This should be mandated training.

6. Strategic planning and stimulation of market provision that will enable providers (including new entrants/third sector) to develop community provision at scale which will support young people with autism who require bespoke living arrangements

There is evidence that children and young people with autism are being admitted to inappropriate placements due to a lack of appropriate community provision. A joint programme of work with families, Department for Education, Department for Health and Social Care, NHSE, Association of Directors of Children's Services, and providers is needed to ensure provision at scale that will deliver robust and reliable care close to home.

7. Parents as partners

There are reports from parents of an absence of meaningful involvement in decisions relating to the care and management of their children. Development of a parental rights-based approach is needed to ensure that wherever possible no decision about their child without their involvement or the involvement of the young person is made. This should be enhanced with the introduction of a programme of parental peer support for hospital admissions. Introduction of patient ambassadors for each region will develop networks to facilitate support and advice for parents with children entering inpatient care.

8. Hospital environments adapted for children & young people with autism

There is evidence to show that children with autism are admitted to mental health units as a last resort and that the environments do not meet their needs. No children with autism should be admitted to a mental health hospital in the absence of a mental health need and therefore with a clear therapeutic intent and expected outcomes. Where admission meets this criterion there must have been reasonable adjustments to the environment in keeping with their sensory assessment.

9. Robust escalation processes including a system navigator (keyworker) to co-ordinate those cases of significant concern

There is evidence that when an individual's care pathway becomes complex across partner agencies that lack of joined up working will have an impact on the outcomes. The worker must have the autonomy and authority to work across all partner agencies and instruct change. They must have access to a team of system experts to assist in unblocking or addressing complex issues. Cases for co-ordination would be identified through escalation from providers, commissioners and parents in any part of the system. This would include cases that have been assessed under the Human Rights Framework. There is a commitment in the long-term plan for the development of a key worker role for children and young people with a learning disability, autism or both who are inpatients (approximately 250 children) and for children and young people with the most complex needs in the community.

The long-term plan implementation framework identifies an inpatient keyworker role that will offer a co-ordinating /supportive/advocacy role for the young person and family.

10. Ensuring the voice of the young person is heard, including strengthening the role and involvement of advocates

There is evidence that advocacy arrangements for CYP, particularly those who are looked after, should be strengthened to ensure that their voices are heard through the pathway. Access to advocates should be considered on an opt out basis. National training standards should be developed for all advocates (CYP and IMHA) alongside mandated standards for professional supervision. Advocacy organisations should produce biannual reports which demonstrate and assure their responsibilities and impact for CYP. In addition, a route of escalation for advocates should be developed to support the raising of concerns to commissioners and system navigators when issues at provider level are not resolved.