Norfolk Safeguarding Adults Board

Safeguarding Adults Review:

Douglas

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"It's nobody's fault, I've been in a kind of pain for a long time, and I love you all".
Douglas, 2022

1. Introduction

1.1 Purpose of review

The purpose of a Safeguarding Adult Review (SAR) is described in the Care Act[1] statutory guidance as:

> "*seeking to determine what the relevant agencies and individuals involved in the case might have done differently that could have prevented harm or death. This is so that lessons can be learned from the case and those lessons applied to future cases to prevent similar harm occurring again. Its purpose is not to hold any individual or organisation to account*"[2].

Douglas was 21 years of age when he tragically took his own life in July 2022. During his brief life he had experienced a range of circumstances including being a young carer, living with neuro diversity and a range of other both physical and mental health conditions. SAR Douglas was commissioned as a SAR under section 44(4)[3] of the Care Act (2014). This section of the Care Act 2014 permits a Safeguarding Adults Board to arrange for there to be a review of any case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs).

The methodology used in this SAR endeavours to understand professional practice in context, identifying systemic factors which influence the nature and quality of work with vulnerable adults. The intention is to provide a proportionate and meaningful account of what happened from the perspective of the vulnerable adult and their family and to add reflection and learning into the local safeguarding system.

A key aspect of a SAR is for an independent reviewer to work with a review team to develop the learning. In this case, Jo Procter[4] was commissioned to undertake the review. She worked alongside the Norfolk Safeguarding Adult Board (NSAB) Business Manager and a SAR Review Panel which included representatives from the main services involved in this case.

Current SAR guidance[5] stresses the need for proportionality; the partnership was mindful of this guidance and were aware that there have been considerable changes in multi-agency practice since Douglas's sad death.

[1] Care Act 2014
[2] Para14.168, Care and support statutory guidance - GOV.UK
[3] Care Act 2014
[4] LLB (Hons), LLM, MSc, CMgr FCMI
[5] Safeguarding Adults Review Quality Markers - SCIE

The approach taken in this review aims to reflect SAR guidance and to focus on areas where practice still needs to be strengthened. Therefore, there will not be a detailed analysis of all events, only those events directly relevant to the key findings will be presented.

1.2 Methodology and timeframe

As detailed above, a SAR panel was established which included representatives from key partner agencies. These representatives were independent in that they had no direct involvement with Douglas or his family, and no management responsibility for the services that were provided during the period under review.

The following key lines of enquiry were agreed within the Terms of Reference:

1. **Were the needs of the family considered in their entirety (including in all planning and assessments)?**
2. **What was Douglas's lived experience and did agencies fully understand it? How was Douglas's lived experience used to influence the services and support he received?**
3. **What role did transitional safeguarding/preparing for adulthood play for Douglas and how effective was it?**
4. **Was the impact of Douglas being a carer fully explored and understood by agencies?**

The way in which agencies worked together to support Douglas and his family was considered as a golden thread throughout all of the keylines of enquiry.

1.3 Timeline

A key aspect of a SAR is to focus on recent practice, but in this case it was agreed the review may include possible learning regarding the transition from child to adult services. Accordingly, the timeframe agreed for the review reflects this transitional period. The main period considered was: **1 November 2017 to 2 July 2022.**

Whilst this period is the focus of the review, earlier relevant information has also been considered.

1.4 Information

The information used to inform this review was obtained from a variety of sources including;

- Rapid review information,
- Information supplied by Douglas's mother,
- Conversations with family members,
- Individual agency outcome chronologies,
- Individual agency reflective reports,
- Individual records and documents requested by the reviewer,

- Practitioners' information gathering workshop,
- Individual meetings with representatives of the Norfolk Autism Partnership,
- Individual meetings with representatives for young carers and adult carer services.

1.5 Early learning

It is acknowledged Douglas died in 2022 and three years have passed between his death and the publication of this report. It should be noted agencies have not waited until the commencement of the SAR process to start identifying and implementing learning. This early learning is identified throughout the report, examples of agency learning include changes in policy, implementing training and making changes to how assessments are undertaken.

1.6 Family involvement

NSAB offer their deepest condolences to Douglas's parents, sister and extended family members for their loss.

Within this review Douglas's family will be mentioned on numerous occasions; for clarity the term family refers to Douglas's Father, Mother and Sister. All steps have been taken to respect the family's privacy and anonymity. Accordingly, Douglas's parents have chosen names to be used for each family member, these are as follows:

- Douglas (Subject of the review)
- Peter (Father)
- Charlie (Mother)
- Henrietta (Sister).

As with all SARs, the involvement of family is an important part of a review process to ensure the reviewer understands their perspectives and experiences of services provided. Whilst it is not a requirement of the SAR process for families to be involved, where they do wish to be part of the process it can contribute significantly to the learning. In this case, contact was made with Douglas's mother, father and sister, and they all wanted to be a part of the review process.

They were invited to give their views during individual meetings with the Independent Reviewer. They shared several documents and spoke freely about what Douglas was like, the areas of service provision that were of concern to them, as well as sharing their views about what worked well. It is important to note that it is not always possible to fully triangulate family perspectives. Where triangulation has been possible, this has been made clear. Otherwise, when family comments are referenced, these should be interpreted as their viewpoint.

Both parents were keen to point out the difficulty in making sense of the various services involved in their households, including the effort required to navigate the systems and advocate for their son's needs whilst providing care for their daughter. As a consequence, the emotional resources required by Douglas's parents was immense.

Grateful thanks are extended to Douglas's mother, father and sister for the time, commitment, and patience they willingly gave in being part of this SAR.
Their steadfast commitment to improve outcomes, and to prevent other families from suffering such unbearable loss, cannot be commended highly enough.

1.7 Practitioner involvement

Another important aspect of a SAR is to engage practitioners[6] in the review and a front-line practitioner workshop was held as part of the review process. Practitioners and managers were invited to share their views about the services provided to Douglas and his family and to identify single and multi-agency learning. From this workshop and other information supplied as part of the process, it is clear practitioners were deeply saddened by Douglas's death.

2 Context

2.1 The timeframe for this review covers just under a five-year time period, consequently there will be a summary of the context of this case review, but it will not go into great detail regarding the chronology of events. Where particular times or events are pertinent to a key line of enquiry, these are detailed within the narrative relating to this area.

2.2 Douglas was born in 2000 to parents, Charlie and Peter; his sister (Henrietta) was born three and a half years later. All the family members identify as white, British.

2.3 The family lived in the Norfolk area for the duration of Douglas's life. Charlie and Peter separated when Douglas was around ten years of age. Initially, Charlie and Peter lived relatively close to each other and there was a joint custody arrangement in place whereby Douglas and his sister spent a week at his father's home and then a week at his mother's home on a rotational basis. Towards the latter time period covered within this review, Charlie moved so that the children had easier access to education and health settings; Douglas and his sister then spent the majority of their time residing with their mother but continued to spend some weekends with their father.

2.4 The family dynamics, vulnerabilities and needs were complex. Douglas had a range of vulnerabilities, he suffered from Familial Adenomatous Polyposis[7]. As a result of this condition Douglas underwent a total bowel removal in June 2017, and this left him with ongoing toileting issues. Douglas was diagnosed with Autistic Spectrum Disorder[8] (ASD), anxiety with psychotic symptoms, chronic depression, and Coeliac Disease[9].

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[6] The term 'practitioners' is a generic **term** which includes practitioners and clinicians who knew Douglas and /or Henrietta and worked with them &/or who currently work with children/ adults in the Norfolk area.

[7] A rare medical condition which causes hundreds or thousands of small growths in the large bowel

[8] Autism is a lifelong developmental disability which affects how people communicate and interact with the world, What is autism

[9] Coeliac disease is a serious illness where the body's immune system attacks its own tissues when you eat gluten. This causes damage to the lining of the gut and means the body can't properly absorb nutrients from food. Coeliac disease is not an allergy or food intolerance.

He was also a carer for his sister (and at times his mother). Any one of these vulnerabilities would have required support but due to the number of his vulnerabilities, his support needs were comprehensive.

2.5 Henrietta had a rare genetic chromosome abnormality which resulted in global developmental delay and a diagnosed learning disability. These conditions often manifested in physical and verbal aggression and other behaviours, including destroying property.

2.6 Like Douglas, Charlie also had Familial Adenomatous Polyposis which manifested in severe chronic fatigue. She also had some mental health concerns due to stresses from the family and health situation.

2.7 The impact of the catalogue of vulnerabilities and needs was immense, particularly in Charlie's household. Charlie described the sheer number of professionals involved in their lives, the impact of people constantly being "*in and out*" of the house, the barrage of information and the feeling of endlessly fighting for support and services. In terms of Douglas as an individual, he was an avid reader and loved classic books, particularly Russian and American classics. He had a passionate interest in history and politics and commenced studying American Studies at University. His time at university is explored in more detail within the report.

2.8 Douglas was a keen gamer: he loved computer games and was part of a large online gaming community. Although he did not physically socialise with friends, he described the people he gamed with online as his friends and would talk to them for hours whilst gaming. His parents both describe a young man who found it difficult to trust people, struggled with social interaction and didn't easily make friends. As such, it is highly likely he would have found virtual friendships much easier to navigate.

2.9 He was keen to explore the world and visited eight different countries. He had a keen interest in riding motorcycles, which he did regularly with his father. He loved animals and his sister described his love of sloths and gerbils. She also described how he liked different types of music but he would play it too loud.

2.10 During the timeframe covered by this review, Douglas also had some darker periods. Severe anxiety, often presenting as severe sweating, was a theme throughout this review. Douglas had been on various anti-depressant medication from 2017 but was taking no anti-depressant medication at the time of his death. He was deemed to have capacity in accordance with the Mental Capacity Act 2005[10] throughout his adult years.

[10] Mental Capacity Act 2005

2.11 Douglas had ongoing suicidal thoughts from his early teens but told many agencies, including health and education staff, he had mechanisms to distract himself and had no desire or plan to act out these thoughts. Despite these assurances, Douglas did make two attempts to take his own life in 2019 and a third time, in 2022, he was successful. At the time of his death, he was three weeks off his 22nd birthday. It is possible that the inconsistencies between what Douglas told professionals about his suicidal intent and the actions he subsequently took, may be related to social communication difficulties which form part of his autism. This is explored in greater detail within the report.

2.12 Douglas was known to many agencies including community and acute health, educational establishments, and voluntary organisations. Due to his sister, he was known to Children's Social Care and Adult Social Care as Henrietta was open to both services at various points in her life. However, despite his own vulnerabilities and needs Douglas was never open to Children's Social Care or Adult Social Care in his own right. This was a gap in practice and is explored in greater detail within the report.

2.13 When describing Douglas his mother said

> "*Everyone who met Douglas loved him. It was his placid demeanour, his well-considered English. He was so interesting, so knowledgeable and so inspiring. The world has lost a really unique person".*

3 Analysis and Learning

3.1. Key Line of Enquiry 1 - Were the needs of the family considered in their entirety, including in all planning and assessments?

> ***"****Throughout the duration of family life, I don't feel that our situation has been understood by services. There were so many people involved in my household, constantly people coming in and out and having to tell them the same story. There were so many people but no real sense of any progress".*
>
> Charlie 2024

3.1.1. Following the separation of his parents, Douglas spent a considerable portion of his life living across two households (his mother's and father's).

His family, for the purposes of this review relates to both of these households. Based on the evidence submitted for this SAR, it is clear the needs of the family were not considered in their entirety.

Understanding complexity in households in their entirety

3.1.2. As previously described, the needs within the family were immense. Whilst Douglas and Henrietta spent time residing with both parents, towards the latter stages of this review the majority of time was spent at their mother's house and this placed a great deal of pressure on this household.

3.1.3. Within the mother's household, each person (Douglas, Henrietta, and Charlie) had a range of professionals working with them on an individual level and collectively across all three people; the network of professionals supporting the household unit was immense.

3.1.4. There is clear evidence Henrietta received a lot of support from agencies. She attended several support groups and Charlie describes her as enjoying these and getting a lot out of them. There is evidence Norfolk County Council worked with Henrietta and her mother to offer a range of assistive technology that would help Henrietta. These included GPS trackers, Memo planners and Memo dashboards. There was good evidence of Henrietta having a consistent Preparing for Adult Life (PfAL) worker who clearly supported both Henrietta and Charlie through this transition period. This worker established a good relationship with both Charlie and Henrietta and Charlie described the worker as "*making her feel validated*".

3.1.5. However, despite the work being undertaken with Henrietta there is less evidence of how the support needs within Charlie's household were considered in their entirety to include Douglas, Charlie and Henrietta. In a household with this level of complexity this was a significant oversight.

3.1.6. Charlie had physical health conditions leading to chronic fatigue and exhaustion. She was living with a child (Henrietta) who could be sad, angry, and often physically and verbally aggressive. In addition, Douglas had his own vulnerabilities: he was neurodivergent, anxious and at times engaged in self-harming behaviour. Charlie described the constant feeling of being overwhelmed and not knowing which way to turn. She felt she was constantly fighting for support and services and there were endless numbers of professionals that she communicated with regarding Henrietta, Douglas, and herself.

3.1.7. There was some respite provision for Henrietta. Henrietta and Charlie were involved in selecting the respite placement and Charlie described it as a "*well thought out profile*". However, even with the respite placements agreed, this was limited and the everyday stress in the household would have continued to be significant. The ever-increasing boiling pot of emotion and stress within Charlie's household as a whole does not appear to have been recognised or responded to by agencies throughout the majority of this review.

3.1.8. This pressure was exacerbated in June 2022 when a decision regarding funding for a permanent residential placement for Henrietta was deferred. There is evidence of clear thought going into the suitability of this placement and Henrietta and Charlie participated in selecting it. Following the deferment decision, there is evidence of correspondence by the PfAL worker stressing that the "*family are at breaking point, Charlie can't cope, and Henrietta will end up in emergency placement*"; the desperate situation of the household is clear. It was shortly after the decision to defer the placement was made that Douglas took his own life. For clarity, this review finds no conclusions that Douglas's death was directly linked to this decision, but the decision would have undoubtedly caused added stress, particularly on Charlie, and this would have impacted on Douglas on the days before he took his own life.

3.1.9. In 2018, behavioural family therapy was offered to Douglas and Charlie by mental health services. While agency records indicate that the intervention had positive outcomes, Charlie reported that she did not find the therapy helpful. Despite this divergence in perspective, the case provides evidence of a joint therapeutic approach being applied. However, it remains an isolated example of a 'think family' model being considered and implemented, highlighting the need for more consistent and embedded whole-family practices across services.

3.1.10. Effective service provision requires placing the family unit at the centre of intervention. This enables professionals to understand the interconnected needs of all household members and deliver support that reflects the family's collective and individual circumstances. There is clear learning for the partnership around adopting a whole-family approach to assessment and risk. Agencies must consider the physical health, mental health, and additional needs of each member - recognising how these factors interact and influence the family as a whole.

3.1.11. Charlie recalled numerous instances where agencies provided her with leaflets and resources, but no one took the time to explain them. As a result, she was left confused about the support available and how to access it - with no one to help her make sense of the system. While written materials can be helpful, their impact is limited if families do not fully understand their content. This is especially true for families with neurodivergent children, who often face information overload and require more personalised, guided support to navigate complex systems. Agencies must prioritise relational communication over passive information-sharing - ensuring that resources and information is not just distributed but meaningfully explained in ways that meet each family's needs.

3.1.12. The concept of a designated point of contact acting in a liaison support role for families is well-established. For example, police services have long utilised Family Liaison Officers to provide consistent communication and emotional support during critical incidents. More recently, the value of a dedicated professional has been recognised for parents whose children are subject to sexual or criminal exploitation outside the home[11]. In Norfolk the Transforming Care Navigators provide support to a specific cohort of families to help them navigate the health, education and social care system.
All of these roles demonstrate the importance of relational continuity, clear communication, and trusted support in helping families navigate complex and distressing circumstances.

3.1.13. For families with complex and multi-agency involvement, such as Douglas's, agencies working with the family should identify a dedicated liaison person to support the family. This professional should be selected based on who holds the strongest and most trusted relationship with the family. The liaison professional will support the family in navigating partnership systems, explaining processes and pathways clearly. This role is critical in reducing confusion, improving access to support, and fostering trust between families and the professionals working with them.

Recommendation 1

In cases where multiple family members are engaged with various services, multi-agency practitioners should collaboratively identify and assign a liaison professional based on who holds the strongest and most trusted relationship with the family and has meaningful, regular contact. This liaison role, in communication with the other agencies, should take responsibility for helping the family clarify pathways and entitlements, navigate key services and provide consistent, family-centred guidance. This role will provide valuable support to families, improve service navigation, and foster trust between families and support systems. Quality assurance activity should be undertaken within 12 months of publication to evidence the recommendation has been implemented.

Engaging with Fathers and male carers

3.1.14. Mothers are often the main source of information for professionals, and this was clearly evident in this case. The information shared for this review contained multiple records regarding Charlie's involvement in Henrietta's assessments/plans, her views on support services and also her views on Peter and his parenting. In contrast, there was little, if any, information regarding Peter.

[11] https://ivisontrust.org.uk/about-ivison/our-work/partnerships/ -Parental Liaison Officers

3.1.15. As previously described, Charlie and Peter separated when Douglas was around ten years of age and Henrietta was around six.
Following an acrimonious separation, Douglas's parents continued to live relatively close to each other and residency of the children was divided on a 50/50 basis with the children spending a week with Charlie and then a week with Peter. When Douglas was aged 16, Charlie moved to a different area within Norfolk that permitted better access to health and education settings, at this point the residency arrangements changed, and the children spent some weekends with their father. Consequently, towards the end of the timeframe covered by this review, Douglas and Henrietta spent the majority of time living with their mother, but they still spent a considerable amount of time with their father, and he was an active part of their lives.

3.1.16. Despite the active involvement in his children's lives, Peter was absent from the work of agencies. Based on the information supplied for this SAR, there was no evidence of his involvement within assessments or plans regarding either of his children and no contact with agencies, save for a safeguarding referral made by Charlie following Henrietta returning from a weekend with her father with a bruise (this led to no further action). It should be noted one agency reported they did contact Peter to ask him to be involved in a safety plan assessment, he is reported as declining this request. Peter has no memory of this communication.

3.1.17. An example of the lack of involvement or consideration of Peter is demonstrated within Douglas's Education, Care, Health Plan (EHCP)[12].
The plan had a section devoted to "family"; whilst there is mention of Charlie and Henrietta there is no mention of Peter in the plan. This is despite Peter being an active part of Douglas's life at this time.

3.1.18. Peter describes not feeling involved with the care and support planning for either Douglas or Henrietta. A lack of contact and information from agencies left him in the dark regarding concerns for his children and not knowing what support they were receiving The lack of knowledge regarding Douglas's mental health concerns was exacerbated by Douglas not wanting to talk about how he was feeling and when asked by Peter how he was, the answer was always "*he was fine*". Peter described how over time Douglas's presentation and behaviour became normalised and he had no knowledge of involvement with agencies that would have made him question this.

3.1.19. The lack of information regarding both Douglas and Henrietta was further amplified by the difficult relationship between Charlie and Peter, which resulted in information not being communicated through this parental route.

[12] An education, health and care (EHC) plan is for children and young people aged up to 25 who need more support than is available through special educational needs support. EHC plans identify educational, health and social needs and set out the additional support to meet those needs.

3.1.20. Agencies' records have multiple recordings regarding Charlie raising concerns about Peter's parenting, stating Douglas and Henrietta did not want to see him. These concerns appear to have been taken on face value and there is no evidence agencies explored Charlie's assertions and/or spoke to Douglas, Henrietta, or Peter to gain their views directly. There is little doubt in the absence of verifying Charlie's concerns, this would have impacted on how agencies viewed Peter and assumptions would have been made regarding his parenting and willingness to be involved.

3.1.21. As a result of the failure to involve Peter, potential sources of support were not considered leaving a fundamental gap in both information and risk assessments. The lack of involvement of Douglas's father in the work of agencies throughout the duration of this case is a significant area of learning for the partnership.

3.1.22. The need to ensure males in households are considered by agencies has been recognised nationally[13]. Fathers are a critical point of reference for all children as they grow up and they have a significant impact on the health, safety, wellbeing and life chances for those children. It is imperative all organisations that work with children and families understand and act on this at all levels of their service provision[14].

3.1.23. It is recognised the practice in this case is not recent, and Norfolk Safeguarding Children Partnership (NSCP) has already taken great strides in ensuring practitioners implement father inclusive practice across the partnership. A range of guides, training and toolkits focussing on keeping fathers in sight are in place.[15] The NSCP have appointed a lead for this area of work to ensure father inclusive practice is embedded across Norfolk. However, whilst progress has been made, there is still a need for further work regarding involvement of fathers and male carers. This is particularly pertinent in cases where the relationship between parents is acrimonious. It is imperative professionals consider all members of a family, including fathers and male carers. Professionals should not take information about parents on face value and ensure that they are professionally curious and make time to check the accuracy of parental views.

Recommendation 2

When assessing risk professionals must consider all members of a family, including fathers and male carers. Information about family members should not be taken on face value and professionals must be professionally curious and make the time to check the accuracy of those views. This is relevant in all cases but particularly in cases that involve more than one household. This approach will be evidenced through NSCP quality assurance activities and shared with the NSAB for assurance.

[13] The Myth of Invisible Men
[14] kfis_good-practice-guide-for-working-with-fathers_press-ready.pdf
[15] Keeping Fathers in Sight: Good Practice Guides | NSCP

3.2. Key Line of Enquiry 2 - What was Douglas's lived experience and did agencies fully understand it? How was Douglas's lived experience used to influence the services and support he received?

> *"Douglas was a sensitive young man who wanted to please people. He was old fashioned, uber polite and never swore. As a child he wanted to join the RAF but due to his health issues this was not possible, his love of airplanes remained with him throughout his life".*
>
> Peter 2024

3.2.1. In the timeframe considered within this review, Douglas spent the majority of time living with his mother and sister. He was the main carer for his sister and Henrietta's health conditions manifested in significant extreme behaviour which could result in both physical and verbal assaults on Douglas and her parents. Both parents described home environments in which Henrietta demanded their attention and often this was at the detriment of Douglas. The information provided for this review reflects this dynamic. There is evidence regarding the views of Charlie, information regarding services and assessments for Henrietta, but proportionally very little information regarding the services and support offered to Douglas and even less reflection of his voice or lived experience.

3.2.2. There is some evidence, in the GP, hospital and education (both further and higher education) records, of Douglas describing his lived experience and appropriate action being taken by these agencies to support him, but this is not reflected across the whole partnership. Douglas's father described

"*not ever really knowing Douglas; he wanted to please people and you were never sure if answers he gave were correct or just the one he thought you wanted to hear*".

The premise of Douglas wanting to please people is exemplified in hospital records which show him as saying he "*didn't want to be a burden to his family*". There is also evidence within agencies' records confirming Douglas often painted a rosier picture of his life than maybe he experienced. As a result of all the factors highlighted above, there is limited evidence that agencies really knew Douglas or his lived experience and this undoubtedly impacted on the services and support that was offered to him.

3.2.3. In the absence of information regarding Douglas's lived experience this section will focus on three main aspects of his life: autism and self-identity, mental health and hearing his voice.

Autism Spectrum Disorder and self-identity

3.2.4. Developing a sense of self, is a crucial aspect of personal growth and adolescence/early adulthood is a critical period for many aspects of evolving identity, including personal goals, motivations, and psychosocial well-being[16]. During this period, adolescents and young adults seek autonomy, particularly from their parents[17].

3.2.5. Douglas straddled several identities (young adult male, carer, university student) each one bringing with it a differing label. Developing self-identity can be difficult for any young person, but as an autistic young adult, navigating the kaleidoscope of sense of identity was even more complicated for Douglas.

3.2.6. Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that affects how individuals perceive and interact with the world around them[18]. This unique perspective often leads to a complex and sometimes challenging self-identity journey[19]. The challenges associated with ASD and social communication can make it difficult for individuals to build relationships with friends and peers, resulting in a lack of sense of belonging and feelings of isolation[20]. In addition, the unique cognitive processing styles of many autistic individuals can result in a different way of perceiving and interpreting the world around them. This can sometimes lead to a sense of disconnection from societal norms and expectations, further complicating the process of identity formation[21].

3.2.7. Charlie believed Douglas had ASD and tried unsuccessfully on numerous occasions to get an ASD assessment. She was advised that the wait for an assessment could be between 18 months to two years. In the end, Charlie arranged a privately funded assessment, which concluded Douglas did have a formal diagnosis of ASD. This assessment and diagnosis took place when Douglas was 17 years old. The reason why an ASD Assessment did not take place earlier in Douglas's childhood is outside the scope of this review, but it does raise learning about the need for autism to be identified as early as possible to ensure support can be put in place.

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[16] Becht AI, Nelemans SA, Branje SJ, Vollebergh WA, Koot HM, Denissen JJ, & Meeus WH (2016). The quest for identity in adolescence: Heterogeneity in daily identity formation and psychosocial adjustment across 5 years. *Developmental Psychology*, 52, 2010–2021.

[17] Meeus W, Iedema J, Maassen G, & Engels R (2005). Separation-individuation revisited: On the interplay of parent–adolescent relations, identity and emotional adjustment in adolescence. *Journal of Adolescence*, 28, 89–106.

[18] Meeting the needs of autistic adults in mental health services
Guidance for integrated care boards, health organisations and wider system partners. (Nov 2024) NHS England NHS England » Meeting the needs of autistic adults in mental health services

[19] Autism and Sense of Self: Identity Development in Individuals on the Spectrum, (2024) Autism and Puberty Understanding Identity in Autism Spectrum

[20] Autism and Identity: Navigating Confusion, Crisis, and Self-Discovery (2024) Autism and Puberty Understanding Autism and Identity Dynamics

[21] Autism and Identity: Navigating Confusion, Crisis, and Self-Discovery (2024) Autism and Puberty Understanding Autism and Identity Dynamics

3.2.8. Developing a positive sense of self is critical for overall well-being and quality of life; for individuals with autism, this process may require additional support and understanding. In many cases, individuals do not accept that they are autistic, and there is mention in one agency's records that Douglas said he had been diagnosed with ASD "*but he does not think this is correct*".

3.2.9. There is limited evidence some agencies were aware of Douglas's needs around autism, understood his lived experience and worked with him to support his needs. For example, a local further education provider recognised Douglas should have an Education, Health and Care Plan (EHCP[22]) and ensured this was undertaken. The college:

- provided pastoral support;
- showed flexibility around his educational needs, hearing his concerns regarding "cameras in the college watching him and making him feel uncomfortable".
- arranged a timetable that was adapted to his needs; and
- provided computer software to support him in his studies.

Charlie described this educational setting as

"*valuing Douglas, his ability and character and being prepared to flex their systems to allow him to stay in a college environment and make friends*".

3.2.10. Douglas also attended a local university and was anxious about starting his course. It was good practice that the University were made aware of his concerns through a local health provider and ensured Douglas was supported through the University wellbeing service both prior to commencing his course and during the time he was studying with them. Reasonable adjustments were made regarding his studies, he was given support to find accommodation and help to access funding opportunities.

3.2.11. It is good practice that (with the exception of the last two appointments) he always saw the same GP. This provided Douglas with a level of continuity and familiarisation and allowed a relationship to build between the GP and Douglas, all of which are crucial aspects for many autistic people[23].

[22] An Education, Health and Care Plan (EHCP) is a legal document that sets out a child or young person's special educational, health and social needs and how those needs should be met. It sets outcomes that the child or young person wants to achieve in life.

[23] Mason, D., Ingham, B., Birtles, H., Michael, C., Scarlett, C., James, I. A., Brown, T., Woodbury-Smith, M., Wilson, C., Finch, T., & Parr, J. R. (2021). How to improve healthcare for autistic people: A qualitative study of the views of autistic people and clinicians. Autism, 25(3), 774-785. https://doi.org/10.1177/1362361321993709

3.2.12. Whilst there were pockets of good practice, this was not apparent across the partnership as a whole. Many agencies had no information regarding Douglas's autism, other than noting he had an ASD diagnosis. Based on the information provided for this review, there is very little other evidence regarding how Douglas felt about his ASD diagnosis or his sense of autistic identity. It is not possible to say with any level of certainty whether practitioners across the partnership explored how Douglas felt about his autism, what his daily life was like and what support he needed. As a result, a huge part of Douglas's lived experience is not known, and this is a significant area of learning for this review.

3.2.13. Each autistic person is different, as are their needs and the support they may require. As a young person (aged 17) with an ASD diagnosis Douglas would have been eligible[24] for a children's social care assessment of his needs. This assessment never took place and was a missed opportunity to offer him and his family support. When Douglas turned 18, he was also eligible[25] for an Adult social care needs assessment to consider what support he needed regarding his autism. Again, this assessment did not take place and was a missed opportunity to offer him support.

3.2.14. An important part of establishing an autistic self-identity is to recognise and where applicable, accept, that you have ASD. It is possible that Douglas did not have this recognition/acceptance as university records indicate Douglas did not want to be screened for ASD. If Douglas did not accept that he was autistic, he may not have felt he wanted to be assessed by agencies and did not seek out an opportunity for this to happen.

3.2.15. Equally, due to the complexities of Douglas's vulnerabilities and the wider household's needs his autism may have been "lost" within the other needs of Douglas and his family. One practitioner described, during the time period covered by this review,

"*there was little knowledge of autism across the partnership*" and work tended to focus on "*a mental health need or learning disability need and not working with autism in its own right*".

In the absence of Douglas's voice, it is not possible to know for certain whether this happened but based on the information received for this review it is highly likely.

3.2.16. Many of the issues regarding autism raised in this report have been recognised within Norfolk. The Safeguarding Adult Board includes an autism representative. In addition, the all-age Norfolk Autism Partnership[26] (NAP) is a collaborative of autistic people, their parents/carers, autism service providers, voluntary and statutory organisations.

[24] S17 Children Act 1989
[25] Care Act 2014
[26] The Norfolk Autism Partnership - Norfolk Autism Partnership

The NAP was established to respond to the Autism Act 2009 and aims to help develop improved services for children, young people and adults who have, or who may have autism.

3.2.17. The work of the NAP has focussed on raising autistic awareness and inclusion and during the time period covered by this report the Norfolk All Age Autism Strategy 2019 to 2024 was in place [27]. The strategy had three aims

- Enabling autistic people and their families/carers to have timely access to and specific support from public and voluntary services (including health, social care, criminal justice system, employment, education, housing and public transport) which is accessible, integrated and focused on outcomes that improve their lives.
- Increasing awareness and understanding of autism.
- Ensuring Norfolk County Council and local NHS bodies will meet their legal duties and how the autism community can help them do it.

3.2.18. From 2019 to 2024 a range of actions were implemented to fulfil the aims of the strategy, these are detailed in the "You Said, We Did. Norfolk All Age Autism Strategy 2019 to 2024" document[28]. Actions included establishment of an Autism Norfolk Forum, development of autism awareness e-Learning[29] and a local supported employment programme was established to provide job coaching to people 18 and over who have Autism and/or a Learning Disability[30]. There was also a one-off additional investment for autism diagnosis which reduced waiting times for adults by 50%.

3.2.19. Despite the improvements in this area, the NAP has recognised further work needs to be undertaken across Norfolk and, in July 2024, the Norfolk All Age Autism Strategy 2024-2029 was launched. This refreshed strategy is supported by an action plan and reflects the improvements that have happened since 2019, as well as the changes that autistic people in Norfolk have said they want to see over the next five years, i.e. from 2024 to 2029[31].

3.2.20. In addition to the work undertaken by the NAP, adult social care and NSFT have each established a network of autism champions within their organisation to raise awareness of autism and champion best practice.

3.2.21. The partnership has recognised the need for early help in autism and, in January 2024, Adult Social Care launched a new autism adult support service which is aimed at individuals with emerging care adult social care needs.

[27] Microsoft Word - Our Autism Our Lives Our Norfolk19_24 v6
[28] https://www.norfolkautismpartnership.org.uk/wp-content/uploads/2023/10/You-Said-We-Did.pdf
[29] Autism Awareness E-Learning - Norfolk Autism Partnership
[30] Working Well Norfolk - Norfolk County Council
[31] Autism Strategy Refresh 2024-2025 Summary

The service was co-produced with autistic people and offers 12-week support to help individuals reach a personal goal. The service links with other services and can help with reasonable adjustments and support the individual into adult social care if needed. The service has now been in place for 12 months and is the subject of a review. One of the significant positives of this service is that the individual does not need to have a formal autism diagnosis, they need to identify as having autism. This service could have played an important role for Douglas had it been in place in 2022.

3.2.22. The NAP has recognised awareness of autism and support systems play a crucial role in fostering both a positive self-image and life chances for autistic people. Family members, friends and professionals can all contribute to creating an environment that validates and supports the autistic experience. This support can help individuals with autism develop resilience and a strong sense of self-worth[32].

3.2.23. With an estimated 700,000 autistic adults and children in the UK[33] there is a clear need for these support structures to be put in place and for the work of the NAP to be promoted. Agencies must ensure that they capture the voice and lived experience of individuals, are professionally curious and ensure what they are being told is accurate. This is pertinent in all cases but particularly relevant autistic people.

ASD and mental health

This section particularly focuses on ASD and mental health, the wider issues involving mental health transitions is addressed on page 25.

3.2.24. Mental health problems affect approximately 70–80% of autistic individuals across all age groups, with anxiety and depression being the most common[34]. In addition, studies have found, autistic adults are at a higher risk of suicide[35], and are up to nine times more likely than non-autistic adults to experience suicidal ideation[36]. Studies have also found there is a sevenfold increase in suicide attempts for autistic people compared to the general population[37].

[32] Siegel, D. J. (2012). The developing mind: How relationships and the brain interact to shape who we are. Guilford Press.
[33] The national strategy for autistic children, young people and adults: 2021 to 2026. July 2021, The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK
[34] The national strategy for autistic children, young people and adults: 2021 to 2026. July 2021, The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK
[35] **Meeting the needs of autistic adults in mental health services**
Guidance for integrated care boards, health organisations and wider system partners. (Nov 2024) NHS England NHS England » Meeting the needs of autistic adults in mental health services
[36]Kõlves K, Fitzgerald C, Nordentoft M, Wood SJ, Erlangsen A. (2021) Assessment of suicidal behaviors among individuals with autism spectrum disorder in Denmark. JAMA Network Open. 2021;4(1) klves_2021_oi_201024_1609777991.04808.pdf
[37] Hirvikoski T, Boman M, Chen Q, D'Onofrio BM, Mittendorfer-Rutz E, Lichtenstein P, et al. (2019) Individual risk and familial liability for suicide attempt and suicide in autism: a population-based study. Psychological Medicine, 50(9): p1463–74.

3.2.25. This increased need for mental health support is often compounded by autistic people facing more barriers to good mental health care than non-autistic people[38]; including difficulty articulating how they are feeling and services with insufficient capacity to meet demand.[39]

3.2.26. In the time period covered by this review, Douglas was under the care of mental health services for a range of issues including, dysthymia, anxiety with psychotic symptoms, depression and self-harm. He received services from both acute and community mental health services. Douglas is reported to have had a long history of suicidal thoughts and there is evidence of two unsuccessful suicide attempts in 2019 before he eventually took his own life in July 2022. There is evidence health practitioners across a range of health agencies spoke with Douglas over many years about his suicidal ideation and suicide attempts. He always maintained that he had no intention of taking his own life and had mechanisms in place to cope when he had these urges. Accordingly, on the two occasions he attempted to take his own life in 2019 a view was formed that these were nonintentional. These incidents are considered in more detail in the section[40] addressing mental health transitions.

3.2.27. Douglas struggled with talking about his feelings, didn't want to be a burden and appears to have often told professionals a rosier version of his life than perhaps may have been the case. It is not possible to say with certainty that this was due to his ASD, but it is likely to have contributed to it. From the information shared with this review, there is little evidence that practitioners considered his suicidal ideation through the lens of his ASD; it is likely that had this been considered, health staff may have explored further their initial perceptions.

3.2.28. Whilst it is problematic to predict with certainty future suicide attempts[41], professional awareness that autistic people are more likely to experience suicidal thoughts and behaviours and are more likely to take their own life is the first step to prevention. Practitioners in all agencies, but particularly those in acute health settings, need to be alert to this increased risk of suicide for autistic people. Often individuals are classified as low-moderate-high risk of suicide based on a combination of their responses to questions posed in a suicide risk assessment and clinician judgment. This approach can be problematic for a group of people who may struggle in their interpretation of the questions and in providing details about how they are feeling.

[38] Hossain MM, Khan N, Sultana A, Ma P, McKyer EL, Ahmed HU, Purohit N. Prevalence of comorbid psychiatric disorders among people with autism spectrum disorder: an umbrella review of systematic reviews and meta-analyses. Psychiatry Res. 2020 p287
[39] As above
[40] P23
[41] Hedley, D., Williams, Z. J., Deady, M., Batterham, P. J., Bury, S. M., Brown, C. M., Robinson, J., Trollor, J. N., Uljarević, M., & Stokes, M. A. (2024). The Suicide Assessment Kit-Modified Interview: Development and preliminary validation of a modified clinical interview for the assessment of suicidal thoughts and behavior in autistic adults. *Autism*, *0*(0). https://doi.org/10.1177/13623613241289493

Consideration should be given to working with autistic adults to adapt suicide risk assessment tools to ensure they fit with the needs of autistic people[42], including improving the questions asked and providing explanations for difficult terms.

3.2.29. Nationally, the need for systemic changes regarding the identification and support for people with mental health concerns, autism and learning disabilities has been recognised. In 2022, the NHS Confederation published a report[43] which set out a vision for what these services should look like in ten years' time, for people of all ages in England. Many of the issues raised in this report resonate with the learning identified in this review.

3.2.30. Locally, the increased suicide risk for autistic people has been recognised in Norfolk and is specifically identified as a theme in the Norfolk and Waveney Suicide Prevention Strategy 2024-2028[44]. The Zero Suicide Alliance[45] has developed specific e-learning on suicide and autism[46] and this training is being promoted through the NAP. This training supports the findings from this review and should be promoted across practitioners within the Norfolk Adults and Children's partnerships. In addition, the learning from this review should be shared with the NAP to inform future strategy review.

Recommendation 3

The partnership should review the appropriateness of autistic people being subject to risk assessments which are based on expressing how they are feeling. The review must be informed by an awareness of the communication difficulties that many autistic people face and their difficulty in accurately expressing their feelings. This work should include specific consideration of how suicide safety planning risk is carried out with autistic people. The NSAB should seek partnership assurance evidence from individual agencies that this review has been undertaken and appropriate remedial action has been taken.

Hearing Douglas's voice

3.2.31. At the start of the timeframe covered in this review Douglas was 17 years of age and legally still a child. The Children Act 1989, stipulates professionals should give due consideration to the opinions of children when making plans to promote their welfare. In reality, the parents' own needs and voice may be louder than the child's[47] and consequently parents' voices may receive more professional attention.

[42] As above
[43] No wrong door | NHS Confederation
[44] https://www.norfolk.gov.uk/media/19642/Norfolk-and-Waveney-Suicide-Prevention-Strategy-2024-to-2028/pdf/mhNorfolk_and_Waveney_Suicide_Prevention_Strategy_2024_to_2028.pdf?m=1734945610917
[45] Zero Suicide Alliance (ZSA)
[46] Autism and Suicide Awareness Training
[47] Williams, T. and Parry, S. (2023) The voice of the child in social work practice: a phenomenological analysis of practitioner interpretation and experience. Children and Youth Review, 148. The voice of the child in social work practice: A phenomenological analysis of practitioner interpretation and experience - ScienceDirect

Often the parental view may conflict with the views of the child[48]. There is evidence in at least one agency's records that Douglas asked that his parents were not contacted directly, and he would speak to them himself.

3.2.32. Generally, parents instinctively want to protect their child, even when they become young adults, and ensure they receive support to achieve their best in life. However, when parents feel that they are having to fight for support and services, parental frustration can often be misinterpreted by professionals as anger or controlling behaviour. This can result in practitioners forming a view of parents that is inaccurate. Sometimes practitioners fail to view parental behaviour through a lens of trauma informed practice and form an opinion that a parent is "difficult" when the parent is actually frustrated and scared that their child is not receiving appropriate support.

3.2.33. There is little doubt in Douglas's situation this was the case. Charlie felt that she was relentlessly fighting for support for herself, Douglas and Henrietta and was best placed to advocate for this. She was aware Douglas

"*did not always tell professionals how he was really feeling*" and could "*say he was ok when he wasn't*"

and this impacted on how services viewed the support he needed.
There is no doubt Charlie had significant amounts of communication with professionals, particularly regarding Henrietta, and at times professionals found this challenging. Whilst the level of communication with professionals was intense, there must be an acknowledgement parents are often doing the best they can in very difficult circumstances and parental fear may be misinterpreted by professionals as anger or frustration. This needs to be responded to in a non-blaming/non-judgemental way and is the basis for developing a trusting relationship between parents and professionals that allows for the reduction in the sense of isolation many parents feel.

3.2.34. Charlie's wishes, views and requests for support for herself and her children were clearly articulated across agencies, but what is less clear is Douglas's views. Practitioners describe Charlie

"*speaking on behalf of Douglas and not allowing practitioners to speak directly to him*".

Within the information shared with this SAR, Douglas's wishes, feelings and voice are less evident, and this is a significant gap in this review.

3.2.35. At points during his life Douglas received support from services on a 1:1 basis[49]; his mother confirmed that he responded most positively during this type of support and opened up about how he was feeling.

[48] Race, T. and Frost, N. (2022) Hearing the voice of the child in safeguarding processes: exploring different voices and competing narratives. Child Abuse Review, 31(6).
[49] Support as young carer, through the higher and further education settings and health appts.

However, for a variety of reasons many agencies have moved away from a model of 1:1 support sessions and replaced them with group activities. For many people this model would be beneficial but for individuals like Douglas, he found it difficult to speak in groups and would withdraw. As a result, an opportunity to hear his voice and understand his lived experience was lost.

3.2.36. There is learning for the partnership around families who have high levels of need and the requirement to ensure all individual's lived experience is understood and their voices are heard. On the whole, Douglas's voice was not captured by agencies either as a child or as an adult and this is a significant gap in this review. Consideration should be given to what type of support is best suited to an individual and where possible 1:1 support should be offered to allow individuals the best opportunity for their voices to be heard and their lived experience to be explored by professionals.

No recommendation has been made in this section as this is addressed under the lived experience section.

3.3. Key Line of Enquiry 3 - What role did transitional safeguarding/preparing for adulthood play for Douglas and how effective was it?

Transitional periods can be an uncertain time for any individual, but they can be particular concern to autistic people and their families due to the heightened uncertainty and change[50].

3.3.1. Child and adult services often have different eligibility criteria: children's services are generally based around welfare and protecting children from harm, whereas adults have a much stronger focus on risk enablement and capacity[51]. As a result, for many children across the country, they cease to have access to services when they reach adulthood. Transitional safeguarding is an approach to safeguarding adolescents and young adults fluidly across developmental stages which builds on the best available evidence, learns from both children's and adult safeguarding practice and prepares young people for their adult lives. It focuses on safeguarding young people from adolescence into adulthood, recognising transition is a journey not an event, and every young person will experience this journey differently.[52] It requires a joined up systemic approach to policy and practice and a move away from a perceived cliff edge service approach that many children face when they reach 18.

[50] The Autism Act, 10 Years On: A report from the All Party Parliamentary Group on Autism on understanding, services and support for autistic people and their families in England, APPGA-Autism-Act-Inquiry-Report.pdf
[51] Holmes, D (2018) Transitional Safeguarding from adolescence to adulthood, Research In Practice, Transitional Safeguarding from adolescence to adulthood | Research in Practice
[52] Bridging the gap: Transitional Safeguarding and the role of social work with adults

3.3.2. Despite the range of vulnerabilities which Douglas had he was not open to children's social care in any capacity. In light of his physical health conditions and role as young carer (considered later in this report) he would have been eligible for assessment by children's social care in his own right[53]. Henrietta had periods of time where she was open to the Early Help Service and Children with Disabilities service and was the subject of a child in need plan. Douglas was living with his sister throughout this period but there are no records that any workers involved with Henrietta raised concerns regarding Douglas. As a consequence, Douglas did not receive support from children's social care and there was no transition from children's social care to adult's social care. In turn, he received no support or services from adult social care as he was not on their radar. This was a significant gap in practice in this case and is discussed in more detail later in this report.

Norfolk's work around transitional safeguarding

3.3.3. Due to the circumstances described above it is not possible to comment on the transitional safeguarding arrangements/ preparing for adult life arrangements in this case but learning in this area has already taken place. In September 2023, the Strategic Lead Partners for Norfolk SAB and NSCP commissioned a joint scrutiny piece of work to establish the current single and multi-agency arrangements for transitional safeguarding in Norfolk. This work was commissioned following recognition from partners regarding increased recurring issues amongst this cohort across several single and multi-agency systems.

3.3.4. The specific aims of this piece of scrutiny were to:

- Establish what the current single and multi-agency arrangements for transitional safeguarding are in Norfolk, focusing on what is working well and areas for improvement.
- Learn from good practice around transitional safeguarding and service models in other parts of the country that could be adapted to improve the safeguarding services available to 18 – 25-year-olds.
- Consider the voice of this cohort of young adults and understand what would make the most difference to helping them prepare for and transition into adulthood.

3.3.5. The fact joint commissioning on such an important subject took place evidences the maturity of the partnership relationships and the recognition of the need to address this crucial area. The scrutiny found transitional safeguarding arrangements across the county was variable. Whilst there were some pockets of good practice this was not across the whole partnership.

[53] S17 Children Act 1989

The scrutiny report identified several areas for development and recommendations were made to support improvements in this area. This report has been accepted, and an action plan is in place.

3.3.6. Whilst safeguarding transitions did not take place in this case, Douglas did have a range of other transitional periods including moving educational settings; securing an apprenticeship; and moving from child to adult health service providers. This section of the report will focus on these areas.

Health Transitions

3.3.7. National guidance and standards are in place to support young people, parents/carers and practitioners in the transition from child to adult health services [54] and, from Douglas's physical health perspective, the transitional move from child to adults' services was considered and well planned. When Douglas was 17, there is evidence of communication between the paediatrician and adult gastroenterologist confirming Douglas's move from paediatrics to adult health services. Douglas was subsequently seen by the adult gastroenterologist and adolescent biofeedback nurse for his ongoing care. The impact of this early correspondence was a supported transition into adult services which does not appear from the GP health records, to have negatively impacted on Douglas's physical or mental health.

Mental Health and Transitions

3.3.8. The transition between child and adult mental health services was not really apparent for Douglas. He was first seen by mental health services when he was nearly 17 and a half years old, following a GP appointment where he had discussed feeling depressed, anxious and self-harming. The GP made an appropriate referral to mental health services and Douglas was assessed, the outcome of which was early intervention and an ongoing assessment. The further assessment resulted in a six-month intervention being offered, which included a focus on anxiety and helping to build social relationships. The intervention, which included family therapy, lasted for nine months and by the time he was discharged Douglas was over 18 and an adult. During this period of intervention Douglas was seen by two consultant psychiatrists, including an adult consultant psychiatrist, who saw him shortly after his 18th birthday. At the point of discharge from the Early Intervention Service Douglas was reported as having an improvement in mood and anxiety levels. He was not seen again by mental health services for almost twelve months and no concerns were raised.

3.3.9. Six days after starting university, Douglas was seen by his GP practice with concerns regarding a spike in his anxiety and suicide ideation.

[54] Transition from children's to adults' services for young people using health or social care services, NICE Guidelines, 2016, Overview | Transition from children's to adults' services for young people using health or social care services | Guidance | NICE

The GP gave advice, signposted and made an urgent referral to the mental health youth team for Douglas to be seen within 120 hours. This referral was received and immediately downgraded to the mental health Early Intervention Service who had previously been working with him. No contact was made with Douglas, but an appointment was made for 14 days' time. Before this appointment took place, Douglas attended accident and emergency (A&E) as a result of an attempt to take his life; he did not require medical treatment but described to staff that he was increasingly anxious about university and was missing seminars due to increasing anxiety. Staff felt this was "*impulsive with regret*" and therefore there was no need for crisis intervention. A safety plan was agreed, and Douglas confirmed that he did not want to see anyone from the Early Intervention Service mental health team as he had an appointment in five days' time.

3.3.10. Two days later he presented at A&E again following a paracetamol overdose. He reported that he had taken an impulsive overdose following an argument between his mother and other family members and

"*he was behind with his studies at university and described his home environment as difficult*".

There was good communication between the mental health trust and university regarding the attempts to take his own life and the university ensured a timely meeting between Douglas and the wellbeing service and a support plan was put in place.

3.3.11. Douglas was clear with the university that he did not want them to communicate with his family about his mental health concerns and he maintained this view throughout his period of study with them. As Douglas had capacity[55] and was engaged with mental health services, this view was respected by the university. Whilst it is clear the university spoke with Douglas regarding contact with his parents, what is less evident is whether there was any exploration regarding whether there was another trusted person who the university could contact to support Douglas. The need to consider trusted adults outside of a familial sphere has been recognised since Douglas's death in 2022 and guidance and resources have been produced for universities regarding suicide[56]. Within this guidance[57] specific mention is made of the importance of families and trusted contacts in suicide prevention.

[55] In accordance with the Mental Capacity Act 2005

[56] https://www.universitiesuk.ac.uk/what-we-do/policy-and-research/publications/features/suicide-safer-universities

[57] Collective-responsibility-collective-action-to-prevent-student-suicide.pdf

3.3.12. The day after his second attendance at A&E Douglas was spoken to by health professionals in an attempt to determine what support would make a difference to him. As Douglas did not display any psychotic phenomena, it was determined that despite the two recent suicide attempts he did not meet threshold for Early Intervention Support. Instead, a plan was made for a referral to be taken on by the mental health Youth Team. Douglas was then placed on a waiting list, but no contact was made for eight months. When support commenced, he engaged well but his care co-ordinator left, and he was placed on another waiting list for a further two months. This situation created a perfect storm: Douglas had made two suicide attempts in very quick succession, but as a result of not meeting criteria for access to early intervention support followed by a period of eight – ten months on a waiting list he received very little support at a crucial time in his life. This provides two significant areas of leaning for the partnership. One relating to the assessment of risk of suicide for autistic people (which has been addressed previously in the report) and the other area of learning relates to support for people who are on waiting lists.

3.3.13. Over the total of ten months he was on the waiting list, Douglas reported feeling increased anxiety as a result of not knowing what the plan was for him and spending long periods of time on a waiting list. It is likely that the anxiety caused by the uncertainty was exacerbated by his autism. There is clear learning for the partnership around how service users (particularly those who are neurodiverse) are supported and communicated with whilst they are on waiting lists.

Recommendation 4

NSFT should ensure processes are in place regarding service users (particularly those who are neuro divergent) being supported and communicated with whilst they are on waiting lists and/ or part way through interventions when they need to be reallocated.

Educational transitions

3.3.14. At the start of the timeframe covered by this review Douglas was attending a local further education college. During his time with this establishment, Douglas underwent surgery for his bowel condition. This resulted in having to take a considerable period of time off college to recover. It is to Douglas's credit that despite this period of absence he continued with his studies. As previously described within this report, the college understood his lived experience and were supportive of his needs. It was during his time in further education that Douglas was privately assessed for ASD, the outcome of which was Douglas was autistic.

As a result of this diagnosis, Douglas was assessed for an education health and care plan (EHCP)[58], which he was subsequently awarded.

The commencement of an EHCP was important for Douglas as it resulted in his education, health and care needs being assessed and a holistic and supportive plan put in place.

One of the advantages of an EHCP is that it is legally binding, with the Local Authority having a legal obligation to implement it. EHCPs are applicable to relevant individuals up to the age of 25[59] and accordingly span the transitions from childhood to early adulthood. Within Douglas's EHCP is his clear desire to complete his A levels and commence studying at university, a desire which he achieved.

3.3.15. Douglas enrolled onto his university course with a start date of September 2019. Prior to commencing his course, the University contacted Douglas to assist with his transition from further to higher education. He commenced his course in September 2019 and continued to live at home and commute to university. The University supported Douglas with this transition: practical support and advice was given and there is evidence of both written communication and in person welfare sessions being held. From the start, Douglas struggled with his transition to university and became increasingly anxious; this appears to have correlated with him telling health professionals he was having a difficult time living at home.

3.3.16. Despite the ongoing support that was offered to Douglas, he continued to suffer anxiety regarding his studies and the University worked with him to enable a deferment of his studies. He left the University in January 2020 and re enrolled in September 2020. Unfortunately, despite the support which the University put in place he still did not settle into university life and left the University in June 2021.

3.3.17. Douglas had an EHCP which applies until the age of 25 but ceases on commencement of a university course. Accordingly, at the point Douglas commenced university, the identified support package within the EHCP stopped. This gap was further exacerbated due to a lack of formal mechanism for previous professional assessments and EHCP plans to be automatically passed to the higher education establishments. As a result, Douglas commenced studying at a university, who were blind to what support needs he had and were totally reliant on Douglas informing them.

[58] An education, health and care (EHC) plan is for children and young people aged up to 25 who need more support than is available through special educational needs support.
EHC plans identify educational, health and social needs and set out the additional support to meet those needs.
[59] Children with special educational needs and disabilities (SEND): Extra help - GOV.UK

3.3.18. It is to the University's credit they worked with Douglas to put a comprehensive support package in place, this included access to wellbeing services, regular 1;1 sessions, support with finances and study. However, this support does not have the same standing as a statutory EHCP plan. It is not within the gift of this review to change national legislation to extend EHCPs to include young adults who are at university, but the partnership should consider developing a local agreement to ensure where local young adults study at a local higher education establishment, EHCPs are (with the consent of the young adult) shared with the higher education provider ahead of them starting their course and there is a continuation of formalised support when they commence their studies.

Recommendation 5

UEA, working with Children Services, SEND and other educational establishments (City College and Sixth Form providers), will lead on developing a local agreement to ensure where local young adults study at a local higher education establishment, EHCPs are (with the consent of the young adult) shared with the higher education provider ahead of them starting their course and there is a commitment to agreeing and supporting the student to access all appropriate and available support as early as possible . This local agreement will be implemented within 9 months of the publication of this report. A copy of this this agreement will be shared with NSAB.

Transition to apprenticeship.

3.3.19. Douglas secured an NHS Care Support apprenticeship and accepted this in April 2022. The apprenticeship was due to commence in August 2022. Autistic people have particularly low employment rates, with fewer than three in ten in work[60] and it is to Douglas's credit that he secured the apprenticeship.

3.3.20. As a result of the apprenticeship not commencing immediately, Douglas had a period of three/ four months where he was waiting for the apprenticeship to start. During this transitional period, agency records evidence Charlie speaking to Henrietta's Adult Social Care worker regarding her concerns about Douglas commencing his apprenticeship and the affect of working 12-hour shifts on his health. There is no evidence that this information was shared with any other agency or professionals working with Douglas.

3.3.21. In May 2022, Douglas saw a GP on two occasions. Although he generally saw the same GP (which was good practice) on these two occasions he saw a different GP each time. Both appointments were recorded as relating to excessive sweating. These were viewed as routine appointments where Douglas is recorded as discussing his plans for the future and his apprenticeship.

[60] New review to boost employment prospects of autistic people (2 April 2023) Gov.uk. New review to boost employment prospects of autistic people - GOV.UK

These appointments were potential missed opportunities to consider further why his sweating had recently worsened, to explore his mental health and reported increasing anxiety, particularly in light of his past history of depression, anxiety and previous attempts to take his own life.

Although Douglas generally saw the same GP, these two GPs were not familiar with Douglas and his mental health history. Although it is not always possible, patients with a history of mental health or social communication difficulties should be enabled to be reviewed by the same GP.

3.3.22. Douglas's anxiety regarding the apprenticeship is likely to have been exacerbated by his autism and he received no specific support from agencies regarding this transition period. Charlie and Peter describe how during this period, Douglas was initially elated at securing the apprenticeship but as time wore on, he became increasingly anxious about the role, what it would entail and whether he would be successful at the job.

3.3.23. The prolonged apprenticeship transition also took place during the initial wave of Covid and national and local lockdowns. Peter described how Covid lockdown had a positive effect for Douglas as the isolation was how he chose to live his life, and this normalised his behaviour. In the apprenticeship transition period, it is probable Douglas was going from feeling relatively comfortable in his isolated Covid existence to having to be part of society again, which would have added to his feelings of anxiety.

3.3.24. Nationally there is support available for young people who are seeking an apprenticeship[61] and advice/ guidance on reasonable adjustments once the apprenticeship has commenced (both in terms of academic study[62] and the workplace[63]) but there is little support regarding the interim period between securing the apprenticeship and starting it. For Douglas, this lack of support in the interim period was critical to his wellbeing.

3.3.25. In the period of time since Douglas's death, Norfolk has established a support service for Norfolk residents with long-term health conditions or physical impairments to get into work and to stay in work. Working Well Norfolk[64] was launched in October 2023 and provides support for Norfolk residents over the age of 16 who have a physical or mental health disability[65]. This service supports people with all aspects of obtaining and staying in work, including supporting people with their concerns around starting a new job.

[61] UCAS, Neurodiversity support for apprenticeships, Neurodiversity support for apprenticeships | Apprenticeships | UCAS
[62] UCAS, Neurodiversity support for apprenticeships, Neurodiversity support for apprenticeships | Apprenticeships | UCAS
[63] Support for apprentices with learning difficulties and disabilities Guidance, August 2024, Support for apprentices with learning difficulties and disabilities - GOV.UK
[64] Working Well Norfolk - Norfolk County Council
[65] As defined by the Equality Act 2010

3.3.26. There is learning for the partnership to ensure autistic people are fully supported in their apprenticeship journey, in terms of gaining and working within the role but also receiving additional support in the interim transition period. This could include having a "buddy" at the new place of work who can show them around their place of work, answer any questions and be a single point of contact for any questions or concerns.

3.4. Key Line of Enquiry 4- Was the impact of Douglas being a carer fully explored and understood by agencies?

> *"My brother was funny and really caring. He looked after me and made me laugh. He made me feel safe".*
>
> Henrietta 2025

Douglas as a young carer[66]

3.4.1. Despite his own health concerns, Douglas took on the role of carer to both his sister, and at times his mother, from an early age and was a crucial support to both of them. Henrietta described how they would watch films together and do lots of art and colouring. His father and mother both described how Douglas enjoyed caring for his sister and it brought him a sense of purpose, whilst acknowledging the pressure that it also placed him under. Whilst Douglas's early childhood is outside the scope of this review it is important to understand the context of the support he received as a young carer.

3.4.2. At age nine, Douglas was identified by his school as a young carer. The school notified children's services and a referral was made to a young carers project. Douglas was assessed and given support through a weekly 1:1 meeting with a support worker from a young carer charity. Charlie and Peter describe Douglas as finding this 1:1 support extremely helpful, and he looked forward to these sessions.

3.4.3. Unfortunately, the funding for this support ended. Whilst Douglas finished middle school and started high school, he received very little consistent support regarding his young carer status until another charity was given the young carer contract for his area. The support was provided by way of a youth club and Charlie describes this organisation as proactive in organising fun events such as paint balling. However, the young carers youth club had a number of participants, and the support was in a group setting and not 1:1. Douglas struggled with this environment both in terms of socialising and talking about his feelings in front of other people.

[66] A young carer' is defined in section 96 of the Children and Families Act 2014 as: '…a person under 18 who provides or intends to provide care for another person…'

Consequently, when Douglas was old enough, he decided to leave the young carers youth club and join the Air Training Corps, which was held on the same night as the young carers youth club.

3.4.4. Charlie and Peter describe there was no follow up regarding Douglas's young carer status after he left the young carers youth club and as a result all support as a young carer completely disappeared.

3.4.5. There is no doubt being a young carer for his sister and mother would have placed pressure on an already anxious young man. His father describes the caring role Douglas undertook as

"*both a blessing and a curse, being a carer gave him purpose, he was hidden in this role, but it was a role that he did well and raised his self-esteem*".

At this time, numerous agencies were working with Henrietta and would have presumably known of Douglas's caring role for her. However, there is nothing to suggest any one of these agencies raised concerns regarding Douglas or suggested he was eligible for a young carers assessment in his own right.

3.4.6. Duties and powers placed on local authorities by the Care Act[67] and the Children and Families Act[68] mean local authorities must offer an assessment where it appears that a child is involved in providing care and they must consider the needs of young carers if, during the assessment of an adult with care needs, or of an adult carer, it appears that a child is providing, or at risk of providing care. This means children's and adults' services must have arrangements in place to assess young carers and ensure that no young person's life is unnecessarily restricted because they are providing significant care to an adult.[69] This does not appear to have occurred in this case and Douglas appears to have fallen off the young carer radar when he left the young carer youth club during his high school years. As a result, the impact of his role as a young carer in his early teenage years and transition from adolescence to adulthood was not known or explored by agencies.
This was a significant gap in this case and is an area of learning for the partnership.

Transition from young to adult carer.

3.4.7. By the time Douglas transitioned from young carer to adult carer he was not on any agencies radar as a young carer and as a consequence there was no formal transition between these two services.

[67] 2004
[68] 2014
[69] Children's society, 2016 whole family pathwaywhole_family_pathway_2016_1st_1_.pdf

Douglas as an adult carer

3.4.8. The evidence regarding how much agencies knew about Douglas's role as an adult carer when he was aged 18-21years is inconsistent. GP records for Douglas and correspondence between Charlie and Henrietta's social care workers demonstrate Douglas's adult caring responsibilities were known but there is nothing to suggest discussions took place with him to further explore this area and what support he needed until Henrietta turned 18.

3.4.9. When Henrietta turned 18 in 2022, it was identified Douglas would be eligible for assessment by a local voluntary adult carers organisation. This assessment was undertaken in June 2022 (shortly before his death in early July 2022). During the assessment Douglas was asked about his health, his caring role, how he was managing at home, how he felt, finances, and work. Using carers star values whereby 5 is as good as it can be, Douglas scored himself at 4 and 5 on every area and said his main concern was support for his mother. Following the assessment, a management discussion took place, and the decision was made to close his case and provide support to Charlie, as this was Douglas's main concern.

3.4.10. At the same time as Douglas was completing the adult carers assessment, Charlie was also completing one. The voluntary adult carers organisation described that it is not usual for them to have two members of a family being assessed as carers at the same time. Despite Douglas telling his assessor that everything was ok, and he was doing fine, Charlie's concern was Douglas and the impact of caring for his sister. Although the two assessments were undertaken by the same organisation, they were completed by two different workers who appear not to have discussed or corroborated the information in each assessment. Consequently, the concerns raised by Charlie regarding Douglas's ability to cope in his caring role does not seem to have been shared with the person making the decision to close Douglas's assessment and offer him no support.
Due to the assessment concluding there were no concerns regarding Douglas, the assessment outcomes were not shared with Adult Social Care. In addition, around the same period as the carer assessments were being undertaken, Douglas was seeing his GP about excessive sweating and feeling anxious.

This lack of information sharing within and across agencies is a perfect example of where a whole family, multi-agency approach would have been likely to result in a better outcome.

3.4.11. It should be noted that the carers assessments were undertaken in 2022 and since then the practice of the voluntary adult carers organisation has evolved and been strengthened. Under current practice, both assessments would be undertaken by the same person or, if undertaken by different assessors, there would be a conversation between them to ensure the details and findings of both assessments were considered holistically before deciding the outcome of the assessments. Douglas also requested that his assessment was undertaken away from the family home, which meant the worker did not have an opportunity to experience the home environment for themselves. Whilst it is important that carers have a choice as to where their assessments are undertaken, there is now an organisational preference that the initial discussions take place in the home environment. The voluntary adult carer organisation have also recognised the need for its staff to have an understanding of autism and how this may affect the answers that are given during carer assessments. All staff have received training on autism and learning disability through Oliver McGowan[70].

3.4.12. The importance of understanding the lived experience of carers, both young and adult, are critical to working with families. Caring responsibilities impact carers everyday life but can also affect aspirations for their future. Many carers (both child and adult) may not recognise their role or fear disclosing their responsibilities due to stigma, cultural expectations, or concerns about professional involvement. As a consequence, they may not want to discuss openly their caring roles and the impact that this is having on them.
The reality is that nationally, as a system we are still failing to identify young carers. In 2024, the school census[71] recorded approximately 54,000 pupils as young carers, marking only the second time this data has been collected. Of these, 21,000 were in primary schools, over 32,000 in secondary schools, and around 500 in special schools or alternative provisions. On average, local authorities identified 337 young carers, though this figure varies widely across regions.

3.4.13. While there has been a slight improvement in identification, with 72% of schools reporting no young carers in 2024 (down from 79% in 2023), the true number remains underestimated. As with Douglas, the result of children not being identified as young carers is that they are often not on agencies radars to transition to adult services for ongoing support.

3.4.14. Since the time period covered by this review, Norfolk has undertaken a lot of work around carers, particularly the need to identify young carers at the earliest opportunity so that appropriate support can be offered.

[70] Oliver McGowan Training Hub

[71] School census 2024 to 2025 - Business and technical specification, version 1.5

Co production work with carers (both young and adult) has taken place to develop resources and assessment tools[72] which encourage a conversation with young carers about their lived experience and hopes for the future. There has been a firm move to ensure young carers are at the centre of the work and conversations and assessments take place at their convenience, on their timescale, and a process for transition to adult services is considered at the early opportunity (based on consent of the young person). Multi agency workstreams have been established to address the issue of early identification of carers. These are aimed at education, carer friendly pharmacies, primary care and emergency services. In a move to think in a more family friendly way, parent carer and young carer assessments now include questions enquiring about all the people in a household who undertake caring duties. A series of recorded interviews with both young carers and parent carers will be launched in 2025. These provide carers with an opportunity to describe what their lived experience is like, including many of the issues raised in this report, such as professionals not understanding a family's everyday lived experience and the pressure carers face on a daily basis. These recordings will be used as part of agencies' workforce development programmes and will be available on public forums to raise the profile of carers across the County.

3.4.15. Whilst positive progress has been made in Norfolk, there remains a need for the partnership to ensure the impact of caring responsibilities, both as a young and adult carer, is understood by practitioners. The importance of considering all members in the household/ households as a Think Family approach should be reinforced and outcomes of assessments must be shared to ensure there is a known umbrella view of the household composition as a whole.

3.4.16. It should be acknowledged not all carers feel comfortable with disclosing their caring responsibilities and conversations should take place sensitively. In accordance with current national guidance[73], practitioners should be actively seeking to identify carers, using opportunities such as school, appointments and home visits to encourage the identification of carers. When identified, this should be flagged on young/ adult carers record and shared with relevant agencies.

Recommendation 6

Practitioners should be actively seeking to identify carers using all relevant opportunities. When identified, this should be flagged on young carers record and shared with relevant agencies. The success of this recommendation will be measured through an increase in formally recognised young carers by Children Services.

[72] Young Carers and Families Support Norfolk | Carers Matter

[73] Support for adult carers | Health topics A to Z | CKS | NICE, Help for young carers - Social care and support guide - NHS

4 Conclusion

4.1. Douglas was a young man, near the start of adulthood. Professionals perceived him to convey a world where he was happy, settled and enjoying life. However, often his reality was far removed from this version of events, and he occupied a much bleaker world where he suffered from anxiety and depression: a world where he did not want to ask for help or be a burden to his family.

4.2. Douglas was known to workers in many agencies some of whom worked directly with him but the majority working with his sister. There were a handful of individuals/agencies who did understand what life was like for Douglas on a daily basis and they flexed their processes to accommodate him, leading to better outcomes. However, to many workers Douglas was invisible, and his lived experience was unexplored. This invisibility, hiding in plain sight, led to Douglas not always receiving the support and assessments that were available to him.

4.3. There is no doubt the complex nature of both Douglas's needs and the needs of the wider household are instrumental to the learning identified within this report. Particularly the need to look at practice through the lens of autism. Ensuring this is considered across all agencies but particularly health services in relation to mental health, suicide and waiting times.

4.4. Many of the issues identified in this SAR are already known - they are national issues that require a national response. Locally, there have been some significant service developments in key areas, and this is important to acknowledge.

4.5. Douglas wanted to do things with his life, he wanted to travel, to read, to broaden his horizons and change the world. Tragically, this opportunity was never realised. In memory of his life, Norfolk SAB are committed to learn from Douglas's story and strengthen service developments to find creative ways to work together across agencies and hierarchies.

5 Recommendations

This review has identified several areas of learning which the partnership should consider. The following recommendations are made to address these areas;

1. In cases where multiple family members are engaged with various services, multi-agency practitioners should collaboratively identify and assign a liaison professional based on who holds the strongest and most trusted relationship with the family and has meaningful, regular contact. This liaison role, in communication with the other agencies, should take responsibility for helping the family clarify pathways and entitlements, navigate key services and provide consistent, family-centred guidance. This role will provide valuable support to families, improve service navigation, and foster trust between families and support systems. Quality assurance activity should be undertaken within 12 months of publication to evidence the recommendation has been implemented.
2. When assessing risk professionals must consider all members of a family, including fathers and male carers. Information about family members should not be taken on face value and professionals must be professionally curious and make the time to check the accuracy of those views. This is relevant in all cases but particularly in cases that involve acrimonious parental relationships. This approach will be evidenced through NSCP multi-agency quality assurance activities and shared to the NSAB for assurance.
3. The partnership should review the appropriateness of autistic people being subject to risk assessments which are based on expressing how they are feeling. The review must be informed by an awareness of the communication difficulties that many autistic people face and their difficulty in accurately expressing their feelings. This work should include specific consideration of how suicide safety planning risk is carried out with autistic people. The NSAB should seek partnership assurance evidence from individual agencies that this review has been undertaken and appropriate remedial action has been taken.
4. NSFT should ensure processes are in place regarding service users (particularly those who are neuro divergent) being supported and communicated with whilst they are on waiting lists and/ or part way through interventions when they need to be reallocated.
5. UEA, working with Children Services, SEND and other educational establishments (City College and Sixth Form providers), will lead on developing a local agreement to ensure where local young adults study at a local higher education establishment, EHCPs are (with the consent of the young adult) shared with the higher education provider ahead of them starting their course and there is a commitment to agreeing that the support identified within the EHCP is continued. This local agreement will be implemented within 9 months of the publication of this report. A copy of this this agreement will be shared with NSAB.

6. Practitioners should be actively seeking to identify carers using all relevant opportunities. When identified this should be flagged on young carers records and shared with relevant agencies. The success of this recommendation will be measured through a year-on-year increase in formally recognised young carers by Children Services who will provide NSAB with assurance evidence.