Safeguarding Adult Review in respect of 'Ben'

Contents

1. Introduction & Circumstances Leading to the Review

1.1 Ben was 57 years old when he died. Ben was reported missing on 3rd November 2018 by the Care Agency. His body was found off the coast of Devon on 5th November 2018. He had not been seen for several days before this.

1.2 Ben had Huntington's Disease. At the time of his death Ben was being supported by several agencies:

- Devon County Council Adult Health & Social Care
- Devon Partnership Trust
- Primary Care (Ben had been registered with two different GP practices during the period of this review)
- South West Ambulance Service NHS Foundation Trust
- Torbay and South Devon NHS Foundation Trust: Secondary Health
- Bay Care, Domiciliary Care Agency
- West County Enabling Service *[NB this service did not supply information to support this review. The review author understands that this service is no longer operating.]*
- Huntington's Disease Association

1.3 The co-ordination of Ben's care and support was initially difficult as so many agencies were involved. There were multi-agency reviews to plan the risk management in relation to changes in physical and mental health as well as Ben's cognition and his decision-making abilities. However, this did not occur until August 2017. At this time the Adult Health and Social Care Team worked closely with the Older Person's Mental Health team.

1.4 Ben's family held a view that a different approach to working alongside Ben would have been more appropriate. They related this back to changes with Ben's needs from 2015. They also raised concerns around the lack of action taken in the days preceding his death. It is therefore from this point in time, that the request for review was considered.

1.5 Ben's case was referred to Devon Safeguarding Adults Partnership (DSAP) in May 2019. Section 44 of the Care Act, 2014 requires *'local Safeguarding Adults Boards (SABs) to arrange a Safeguarding Adults Review (SAR) when an adult in its area dies as a result of abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked more effectively to protect the person at risk. It places a duty on all*

Board members to contribute in undertaking the review, sharing information and applying the lessons learnt'.

1.6 The Safeguarding Adults Review Core Group (SARCG) considered the referral on 6th August 2019 where it was agreed that the above criteria for a SAR was met.

2. Methodology

2.1 The Care Act 2014 Statutory Guidance states that the process for undertaking a SAR should be determined locally according to the specific circumstances of individual cases[1] and that the Safeguarding Adult Board should be primarily concerned with weighing up what type of review process will promote effective learning and improvement action to prevent future deaths or serious harm occurring again.

2.2 The SARCG resolved to consider how reviews can be more effective in terms of balancing the time that agencies are involved in such reviews, timeliness of reviews and learning outcomes that can improve the service provided as partners and as such, the methodology selected was based on a proportionate reflective learning review model. Following which a concise report would be produced that focused on key learning and recommendations. It is intended that this will inform an action plan to inform and improve future practice and partnership working.

2.3 Individual Management Reviews detailing organisations' respective involvement with Ben were requested from those agencies supporting him.

2.4 A multi-agency learning event was convened on 2nd March 2020 which included relevant health and social care professionals from the agencies which worked with Ben in the scope of this review, as detailed in paragraph 1.2.

2.5 Ben's GPs were unable to attend the learning event, so steps were taken to enable their participation in the review. Detailed information regarding their involvement with Ben and their reflections were provided to the Reviewer. The West Country Enabling Service did not attend the event nor provide information regarding their involvement with Ben. The reviewer understands that the enabling service is no longer operating.

[1] https://www.gov.uk/guidance/care-and-support-statutory-guidance/safeguarding

2.6 The purpose of the event was to establish whether there are any lessons to be learnt from the circumstances of the case leading up to Ben's death and about the way in which local professionals and agencies work together to safeguard adults at risk. The event was facilitated by the Devon Safeguarding Adults Partnership Safeguarding Practice Lead and the Clinical Commissioning Group Safeguarding Designated Nurse.

3. Process and Scope

3.1 Terms of Reference and a reflective learning event plan were agreed in February 2020. The scope of the review takes account of the events in the life of Ben in the time when he was a resident of Devon **- 01/01/15 – 06/11/18** but briefly summarises any relevant history prior to the time in scope.

3.2 Key questions explored during the review are:

- Did health and social care staff have the experience, skills and confidence when supporting Ben who had a diagnosis of Huntington's disease?
- Were teams clear on referral criteria into other organisations / teams?
- Were there any blocks in getting referrals into other organisations e.g. mental health services and how did staff resolve these?
- Should a mental capacity assessment have been undertaken regarding Ben's choices regarding medication compliance?
- Did all professionals clearly understand the risk of Ben's lifestyle choices, and was this based on evidence or feelings (including staff perception of Ben's risks regarding suicide)?
- Did staff believe that there is adequate health and social care support in Devon for people suffering with Huntington's disease?

4. Family Engagement

4.1 Significant people who know a person are often best placed to help to understand what happened. It follows that family members and friends of the person can help to identify what lessons should be drawn from the tragedy, so it is important their voices are heard. Ben's ex-partner, his brother in law and Ben's youngest daughter had very regular contact with Ben throughout his illness and his time living in Devon.

4.2 Ben's family were informed of the decision to undertake a SAR in September 2019. In February 2020 further contact was made with Ben's family to ask if they wanted to take part in the review and how they wanted to do this. Ben's family decided to share their understanding of what happened and why in writing. This included their thoughts, memories and a point of view on the circumstances around Ben's death. This helped to build a comprehensive picture of Ben and of what happened before his death. The information they shared influenced the development of the terms of reference for the learning event and review.

4.3 A draft review report was shared with Ben's family to allow them the opportunity to check for factual accuracy and provide any additional comments they would like the report author to consider.

5. Relevant History Prior to Time in Scope & Key Events

5.1 Ben was described as intelligent, sensitive, tenacious and determined. He loved travel, nature and walking. He also enjoyed music, reading, poetry and art. He was a previously skilled classic guitar maker and taught carpentry. Ben was separated from his long-term partner. He had two daughters, one from a previous relationship. His eldest was born in 1983, and youngest was aged 18 at the time of his death.

5.2 Ben was diagnosed with Huntington's Disease in **1993** whilst living in Gloucestershire. Ben was the youngest of five siblings. Three out five of the siblings (including Ben) inherited Huntington's disease from their father. His brother died from the disease in 2011. His sister, with whom Ben was said to have been very close, died more recently in July 2018. She was two years older than him.

5.3 Huntington's Disease is an inherited condition that causes the progressive breakdown (degeneration) of nerve cells in the brain. It is caused by a faulty gene that results in parts of the brain becoming damaged over time. If a parent has the faulty gene there is a 50% chance of children developing the condition. Genetic testing is available to determine if the faulty gene is present. If a person has the faulty gene, then they will develop the disease. There is no cure or treatment to slow the progression of the disease.

5.4 A wide range of symptoms usually start at 30 – 50 years of age but can begin earlier or later. It gets worse over time and is usually fatal after a period of up to 20 years. Symptoms of Huntington's disease can include:

- Difficulty concentrating and memory lapses
- Depression and mental health problems
- Stumbling and clumsiness and increasing immobility
- Involuntary jerking or fidgety movements of the body called chorea movements
- Mood swings, personality and behaviour changes
- Problems swallowing, breathing and speaking

5.5 **Between 2003 and 2005,** Ben's health difficulties and associated symptoms were becoming worse. His ill health was said to be having a detrimental effect on his relationship and his youngest daughters' wellbeing. Ben and his partner separated in 2005 but she was a continuing presence in his life offering a great deal of emotional and practical support. Ben continued to have regular contact with his youngest daughter supported by his ex-partner. In 2006, Ben's eldest daughter learned that she had also inherited Huntington's Disease. Ben didn't have much contact with his eldest daughter after she married in 2012 as she was finding his illness and related behaviour too much to cope with on top of her own situation.

5.6 From **2010,** Ben was receiving Mental Health Services in Gloucestershire. This included securing funding to employ a Personal Assistant for 10 hours per week.

5.7 Ben moved to Totnes in Devon from Gloucestershire in **2012** with the support from his youngest daughter, ex-partner and her brother. Gloucestershire referred Ben to mental health services in Devon. The referral was not accepted by mental health services as it was felt Ben did not have a mental health need, rather his needs related to Huntington's Disease. Mental health services referred Ben to the specialist Huntington's Disease service who accepted the referral. The Huntington's Disease service provides specialist assessment and review within a clinic. There is not a community aspect to the clinic.

5.8 In **2014,** Devon County Council Adult Social Care arranged an Occupational Therapy assessment. Ben was described as fiercely independent and not wanting services. His GP made a referral to Mental Health services in **October 2014** following a suspected overdose and concerns raised by neighbour regarding poor hygiene. A referral was opened to the Community Mental Health Team and several attempts were made to arrange an appointment for a mental health assessment with Ben. Ben cancelled appointments offered throughout October and November and then stopped communicating with the team. The Community Mental Health Team persevered and were eventually able to meet with Ben at

his home address in December 2014. The outcome of this assessment was that Ben was not considered to be severely depressed but mildly so and it was felt that most of his issues were due to isolation & being on his own away from family. His self-harm and suicidal risk were assessed as low. It was noted that he is naturally upset by his condition & loss of skills as well as his sister's progression of Huntington's Disease. The Community Mental Health Team decided to follow up with a local community charity supporting Ben regarding help for keeping various appointments, help with housework/shopping and befriending.

6. Key Events Within Time in Scope

6.1 In **2015,** Ben was still living independently with minimal support from a local community charity which provides support with paperwork, shopping etc. However, Ben was having housing problems and wanted to move back to Gloucestershire to be nearer family. Adult Social Care carried out an assessment around his housing needs. Ben declined a full Care Act assessment. Housing options were being explored but did not come to fruition as accommodation suppliers felt their options were unsuitable for Ben's needs. Family were in regular contact with Ben and were proactively trying to support him in securing suitable housing in Gloucestershire.

6.2 Ben's behaviour was becoming more erratic. In **June 2015,** Ben was seen by a Consultant Psychiatrist who felt his needs were linked to Huntington's Disease and not mental health, as a result the Community Mental Health Team said they were unable to provide a service. Ben was offered follow up by the Consultant Psychiatrist but declined this.

6.3 In **November 2015,** consideration was given by the Consultant Psychiatrist regarding use of a Mental Health Act Assessment. However, it was felt that Ben was not presenting with symptoms of a nature or degree that warranted a referral for a Mental Health Act Assessment. His presentation was described as variable and chaotic, and the main risk was of poor engagement and aggressive outbursts. It was agreed that due to Ben's chaotic behaviour and poor engagement with services (neurology, Community Mental Health Team etc) that the Consultant Psychiatrist would offer two further appointments, spacing them out over time. The appointment dates/times would be shared with various key workers involved with Ben to maximise the possibility that he is made aware of these dates and encouraged to attend.

6.4 In **April 2016** Ben allegedly assaulted a neighbour and further concerns were raised regarding his ability to self-care. The GP referred Ben to the Approved Mental Health

Practitioner Hub for a Mental Health Act assessment. At the same time, the Community Mental Health Team discharged Ben back to the GP based on their assessments to date (Ben had not been taken on by the Community Mental Health Team but they had offered him a series of assessment appointments with which he did not engage fully). The Community Mental Health Team held a view that as Ben would be assessed under the Mental Health Act this would provide a second opinion on whether Ben comes under the remit of mental health or not.

6.5 The Approved Mental Health Practitioner Hub considered the referral on **21st April 2016**. It was agreed that based on the information from the GP and from Housing it was appropriate to plan a more low-key intervention rather than going straight to a Mental Health Act assessment. The risk of a compulsory psychiatric admission was not indicated. Instead, the plan was for an Approved Mental Health Practitioner to undertake a joint visit with Housing in order to assess Ben's mental health needs with a view to considering which service(s) is best placed to support him with the psychological and behavioural symptoms of his Huntington's Disease (e.g. the Community Mental Health Team, acute admission, or more specialist supported housing)

6.6 A Consultant Psychiatrist, an Approved Mental Health Practitioner and a housing support worker visited Ben at home on **22nd April 2016**. This was a visit to help plan immediate support rather than a full assessment. It was noted that Ben has marked repetitive and rapid, jerky, involuntary movements which is known as 'choreiform movements', but no other obvious symptoms which are common neuropsychiatric sequelae of Huntington's disease. However, Ben is impulsively aggressive towards others in his housing complex. The Consultant Psychiatrist felt it is extremely likely that Ben's frontal lobe functioning in his brain is impaired due to the Huntington's disease. This leads to impulsive aggression for which he cannot be held responsible, in the same way as someone without Huntington's disease may be. This is reflected in the neighbour's reluctance to ask for charges to be brought against Ben and the police to prosecute him. It was observed during the visit, that Ben's medication was strewn about in half-full boxes on the table. The Consultant Psychiatrist contacted the GP by phone to confirm what medication Ben is prescribed and the doses. The plan following this visit was for Ben to be prescribed 'Risperidone' daily by the GP, for support workers to support and prompt Ben to take his medication and for medication to be provided in blister packs. The Consultant Psychiatrist planned to request follow up by the Community Mental Health Team. However, this could not be arranged as Mental Health Services are not commissioned to provide neuropsychiatric services. The Community Mental Health Team agreed to provide advice to the GP as needed.

6.7 **Throughout 2016,** there was a significant change in Ben's health in relation to his Huntington's disease and other physical health problems. Ben's needs were increasing, and his behaviour became more erratic. Ben was in and out of hospital due to falls. He reported episodes of dizzy spells. Adult Social Care were struggling to know who to communicate with in order to coordinate Ben's various health appointments with which he needed support in order to engage.

6.8 Ben's housing was still unsettled and his relationships with his family in Gloucestershire became difficult. All of this appeared to impact on Ben's ability to cope with daily life. In October 2016, Ben was evicted from his address in Totnes. He sourced his own accommodation and moved to a flat in Dartmouth but was still wanting to move back to Gloucestershire. Ben's eldest daughter, son in law and brother were concerned about the prospect of him returning due to the impact of his behaviour on family. Ben's youngest daughter, ex-partner and her brother were trying to facilitate a move back to Gloucestershire in the hope of better all-round care.

6.9 In **November 2016,** the GP referred Ben to Mental Health Services for depression and impulse control problems. The Older Persons Mental Health team accepted the referral despite Ben not fitting their criteria in terms of age (65+).

6.10 In **December 2016,** Ben's physical health was deteriorating and he was still refusing commissioned services. Ben had limited extended support in the local area.

6.11 On **6th February 2017,** domiciliary care was commissioned and sourced for Ben. The care package consisted of two half hour visits a day to support with household domestic tasks, maintaining Ben's nutritional intake through the provision of meals and ensuring Ben is safe when showering. Two members of staff were required at each visit. It is recorded that this is due to the risks identified around Ben's behaviour towards others. An enabling provider was also commissioned to support with his financial matters, obtaining shopping and accessing community activities. Adult Social Care reported issues with the provider of enabling support but were unable to source an alternative provider due to there being few providers of such a service in the Dartmouth area. They were unable to identify any other providers who were prepared to travel to Dartmouth.

6.12 On **17th February 2017,** a Care Worker called for an ambulance due to concerns Ben may have taken an overdose. Paramedics attended and requested a visit urgently by a

doctor as Ben was refusing to be conveyed to hospital by the paramedics. Subsequently a duty doctor visited and on arrival at his flat found a lot of loose medication out with his blister packs, including 140 tablets of 'Venlafaxine' and numerous 'Tegretol' tablets, both of which are dangerous if taken in overdose. Ben continued to refuse to go to hospital. It was inconclusive whether Ben had taken an overdose. However, to ensure that immediate measures were taken to help Ben manage his medication more safely, the decision was taken by the duty doctor to change Ben's prescription from a monthly to a weekly supply.

6.13 Ben's behaviour reportedly deteriorated from this point and he became much more challenging and aggressive to domiciliary care staff. Care staff perceived this to be because he felt he had lost independence and was angry that he was reliant on others for his medication. More frequently Ben was not at home when care workers visited. They would often see him out and about in the local area when they were due to visit.

6.14 On **19th June 2017,** a referral was made for a Mental Health Act Assessment following a reported overdose. Care workers had called an ambulance and paramedics assessed Ben, advising him to go into hospital for a check-up. However, Ben refused this option. The Approved Mental Health Practitioner Service liaised with the Older Persons Mental Health Service in order to identify a suitable care pathway. It was felt that given the complexity of the issues and the need to carefully consider the care pathway in a multi-agency and multi-disciplinary way, it would be best if a mental health (not Mental Health Act) assessment was undertaken as soon as possible by the Older Persons Mental Health Team with input from other agencies. The referral was left open to the Approved Mental Health Practitioner Service pending contact with Older Persons Mental Health Team.

6.15 A Consultant Psychiatrist from the Older Persons Mental Health team saw Ben at home with an Approved Mental Health Practitioner on **20th June 2017.** The outcome of the assessment was that there was not a present indication to arrange a Mental Health Act assessment as psychiatric admission was not currently indicated. It was suggested that Ben's mood is very reactive to situations and his aggressive outbursts are secondary to poor frontal lobe functioning as a result of his Huntington's Disease. Although Ben reported that he enjoyed living in Dartmouth, it was noted that he was very socially isolated with no friends or family nearby. It was felt that a professionals meeting was needed as a priority, in order to establish a way forward with Ben's care and support, and that this must ideally include representation from the GP practice. A professionals meeting was originally booked for June 2017 but was postponed as the Older Persons Mental Health Team were unavailable.

6.16 Adult Social Care convened a risk management meeting in **August 2017.** The meeting was attended by Ben's Social Worker and Community Health and Social Care Team Manager, Consultant Psychiatrist, Approved Mental Health Practitioner, Senior Mental Health Practitioner and Clinical Team Leader from Older Persons Mental Health Service. Ben's brother-in-law was invited to the meeting. He sent his apologies and received a copy of the meeting minutes. Absent from this meeting was the Huntington's Disease Advisor, the Police and Ben's GP. All professionals in attendance felt that the introduction of controlled access to his medication may result in unintended consequences for the care staff or others (there were fears about his increasing aggression). Ben was insistent that he wanted to have control over when he takes his medication and is not prepared to be consistently at home at the times when his domiciliary service visits. He was consistently assessed as having mental capacity to take such decisions. The Care Agency were asked to continue to observe/monitor Ben taking his medication without intervening. It appears from the information available that this was not communicated to the GP.

6.17 In consultation with Ben the GP reverted Ben's prescription back to monthly in **January 2018**.

6.18 In **June 2018,** a Safeguarding Adults Meeting was convened at a Community Hospital as professionals felt the risks to Ben's health had increased. Unfortunately, neither Ben's GP nor a representative from the Care Agency could attend. Therefore, all agreed the meeting needed to be re-convened in a more localised setting to support key professionals to attend.

6.19 Ben's eldest daughter, son in law & brother had disconnected with him but briefly reconnected with him following his sister's death in **July 2018**.

6.20 The re-convened Safeguarding Adults Meeting took place in **August 2018** at Dartmouth Medical Practice. A Nurse Practitioner from the surgery attended the meeting on behalf of the GP.

6.21 Later that month Ben turned up at the Community Hospital wanting help and willing to accept support. The Older Persons Mental Health worker and a Social Worker saw him there.

6.22 The Huntington's Disease Advisor knew Ben well; he visited Ben at home in **September 2018** and was concerned about a number of things. Ben looked dishevelled and was wearing dirty clothing. His flat was very unclean and the boiler was broken leaving him with no hot water or heating in the flat. No one had acted upon this by contacting the landlord to get it fixed. The Huntington's Disease Advisor was unaware what the commissioned package of support looked like (what the care workers had been commissioned to do and when they are meant to be visiting). He passed on his concerns regarding these matters to Ben's Social Worker.

6.23 Throughout their involvement (February 2017 – November 2018) the Care Agency was struggling to fulfil the package of support. During the 626-day period, two Care Workers were assigned a total of 691 care visits. Ben was either not present at home or did not answer his door or phone when Care Workers attended on 219 of the 691 planned visits. This was identified early in the Care Agency's involvement and changes to Ben's care plan were made but the pattern of Ben being absent from home continued with increased frequency. Care Workers who were successful in entering his flat found they could complete minimal work when they were there, as Ben would not tolerate them being in the flat for a great length of time. Care Workers were struggling to get cleaning done because of this. Additionally, Ben declined support with personal care and food preparation. Some professionals felt that Ben had lost faith in his Care Workers as he believed they were not being supportive about letting him manage his own medication through the GP.

6.24 In **October 2018,** Ben went missing. The Care Agency report:

- 22nd October: Ben was last seen at his home address by care workers
- 23rd October: Ben was not at home when they visited
- 24th October: Ben was not at home when they visited. The record player could be heard from inside his home. Ben was later seen by Care Workers at a local café.
- 25th October: Ben was not at home when they visited. The front door was unlocked.
- 26th October: Call received from the post office advising that Ben was there.
- 27th October – 2nd November: Ben was not at home; the front door was unlocked. Care Workers checked the property but did not lock the door on leaving as they were concerned that Ben might not have his keys and be able to get back in.
- 3rd November: Ben was not at home; the front door lock was broken, and his property and belongings were everywhere. The Care Workers reported to their office that Ben has not been seen for several days. This was the first time they reported his absence to their office.

6.25 On 1st November Ben's ex-partner and her brother reported to Adult Social Care that contact with Ben had been lost and expressed their fear.

7. Key Themes / Areas where Learning has Occurred

7.1 Experience, Skills and Confidence of Staff Working with Huntington's Disease

7.1.1 Adult Social Care's focus during 2015 was on Ben's housing needs. Ben was described as 'fiercely independent' and was very clear in terms of his wishes to return to live in Gloucestershire. Adult Social Care were acting with concern for what matters to Ben however this was possibly a missed opportunity to work with Ben earlier to build relationships and think about future planning as Ben's condition deteriorates.

7.1.2 The informal support provided by a local community charity in Totnes appeared to work for Ben as this support could be flexible. However, professionals recognised that the charity did not have the skill sets, nor was it within their remit to provide the level of support Ben required to fully meet his needs. Finding flexibility in a formal package of care is a commissioning challenging.

7.1.3 Ben consented to a formal package of care which commenced in February 2017. Adult Social Care had found it difficult to source and commission care in Dartmouth during this period as there were few providers in the Dartmouth area. The assessment for 'double-handed' care increased the difficulties with sourcing the package. There is now a block contract in place with one care provider which has eased this difficulty.

7.1.4 The Wellbeing Principle Section.1 of the Care Act (2014) is fundamental to decision-making processes. The Wellbeing Principle is clear that in undertaking any decision-making under part one of the Care Act (care and support assessment and care and supporting planning processes), there is a duty to promote wellbeing. There was a focus on outcomes in the care and support assessment and it was set out where it was considered that the inability to achieve the outcomes would have a significant impact on Ben's wellbeing. However, assessments were not 'strengths-based' (a core component of social care practice) and instead focussed on issues and risk. This influenced the care planning process. The term 'strength' refers to different components that support or enable an individual to deal with challenges in life in general and in meeting their own needs and achieving their desired goals. Strengths-based assessments look at what can be used in the person's internal resources (their

abilities, skills, knowledge, potential etc.) and external environment (information and advice, voluntary sector support, health resources/therapies, equipment and technology etc.), to help them remain independent and get to where they want to be. To achieve the benefits of a strengths-based approach for people, a full picture of the person's situation should be built. This should include a focus on their skills and abilities, as well as issues and risks.

7.1.5 Care plans magnified the perception of risk from Ben to others. A double handed package of care was requested based on risk posed by Ben to others. Ben had been verbally aggressive to family members and professionals, and physically assaulted his ex-brother in law. Therefore, a double handed package of care was considered to be a reasonable risk mitigation. It is also known that the GP service made their own independent risk assessment for Ben to be seen with two people present. However, a key question is what impact this had on Ben's wellbeing and his wiliness to engage with support? The content on risk is relevant but there was an absence of personal details and person-centred planning within the care plans. Had the risks been balanced with Ben's strengths and personal goals this would have provided a person-centred perspective and enabled the professionals supporting Ben to understand his perspective. Ben was well known to the Huntington's Disease regional advisor who could have been contacted to assist with care planning. However, this did not happen.

7.1.6 What the care and supporting planning processes failed to do was connect professionals with each other and care providers, in order to make best use of the available resources to help Ben lead a more independent and fulfilled life and achieve better personal outcomes.

7.1.7 In Dartmouth, there were limited options in terms of care provision and it was acknowledged by the professionals supporting Ben that the care agency sourced did not necessarily have experience in supporting people with a diagnosis of Huntington's Disease. Huntington's Disease symptoms can vary from day to day and care professionals need to have the confidence to be flexible in their approach. On reflecting at the learning event, the care agency acknowledged that their Care Workers did not initially feel equipped in supporting someone with Huntington's disease. They relied on the information provided within the commissioned care plan which they felt did not provide a great deal of knowledge of Ben as a person or of how his condition affects him. It is possible that the perceived risk of aggression impacted on their care delivery as there was an apprehension by care workers around triggering a response.

7.1.8 More could have been done to utilise the expertise of both services and family members with relevant experience.

Learning Point 1: *Care plans should be informed by a strengths-based assessment to provide a full picture of the person's situation. This should include a focus on their skills and abilities, as well as issues and risks.*

Learning Point 2: *All health and care professionals should proactively engage the support of condition-specific specialist services in their assessment and planning of care e.g. The Huntington's Disease Association.*

7.2 Multi-Agency Processes and Criteria

7.2.1 There appeared to be a different threshold for access to secondary mental health services in Devon (as opposed to Gloucestershire) at the time Ben first moved to Devon. He was previously in receipt of community mental health services in Gloucestershire; however, Devon Community Mental Health service assessed that his needs were related to his Huntington's Disease diagnosis and not mental health. As the Community Mental Health service in Devon is not commissioned to provide a single identified 'neuropsychiatric care[2]' service, Ben did not receive community mental health support. A referral was not at that time passed to Older Persons Mental Health team as their service criteria is that a person is 65 or older.

7.2.2 Ben was referred to the Huntington's Disease service and whilst this is an excellent resource for specialist assessment and review, this is within a clinic and this model did not suit Ben. There is not a community aspect to the clinic and to work well, there needs to be joint working where the specialist knowledge from the clinic filters down to the local work in the community.

7.2.3 Huntington's Disease is classified as a neurological condition and is considered nationally to fall under the heading of "long term conditions". An impact of Huntington's is that there may be some mental health presentations which arise due to the nature of the condition.

[2] Neuropsychology is a branch of psychology that is concerned with how the brain and the rest of the nervous system influence a person's cognition and behaviours. It often focuses on how injuries or illnesses of the brain that affect cognitive functions and behaviours.

7.2.4 The Neurological Alliance Consensus Statement on mental, emotional and cognitive health provision[3] is relevant to this review. Point 5 within the Statement says every person with a neurological condition should *'never be denied access to mental health services on the basis of having an organic brain condition, unless they can be referred on to more suitable service.'*

7.2.5 It is relevant to consider the disjointed nature highlighted by this review of Devon mental health commissioning arrangements for people with a diagnosis of Huntington's Disease. In Devon there are several commissioned services within the community, both for long term conditions and mental health, which may be able to support a person's mental health needs. The suitability of the service would be dependent on a person's presentation, stage and primary need and diagnosis. In Ben's case there does not appear to have been consideration of alternative services to provide support. This suggests a lack of awareness across the health and care system regarding the services available for people with a diagnosis of Huntington's Disease.

7.2.6 NHS Devon CCG have confirmed that it is not felt there needs to be a review of NHS Devon CCG's commissioning structure arising from this case [see appendix 1 for more details]. However, there are two areas of review scheduled which will support future cases these are:

- A review of smaller community-based contracts to ensure their specifications are up to date, meeting local need and supporting NHS long term plan ambitions. The Specialist Huntington's Disease Advisory Service will form part of this review.
- Development of a new Community Mental Health Framework for adults and older adults with common mental health conditions and severe mental illness. The development of a new model is in line with NHS Long Term Plan Ambitions and national Community Mental Health Framework Guidance. National guidance requires greater integration with primary care and wider community-based services along with increased Voluntary, Community and Social Enterprise sector connectivity.

[3] https://www.neural.org.uk/wp-content/uploads/2019/06/Mental-Health-Consensus-Statement.pdf

Learning Point 3: *There is an apparent lack of awareness across the health and care system regarding the range of services available for people with a diagnosis of Huntington's Disease, the criteria, the limitations of the services, and how these services can be accessed.*

7.2.7 Initial agreement of agencies to joint work and identifying the correct agencies to work alongside Ben was challenging. In January 2016, the Community Mental Health Team was liaising with the Older Persons Mental Health Team to clarify which team could offer the most appropriate support to Ben. When Ben moved to Dartmouth, the Older Person Mental Health team were flexible and agreed to work with Ben despite him not fitting their age criteria. At the time it was felt that the Older Persons Mental Health Team had more specialist skills in working with people with Huntington's Disease.

7.2.8 Professionals noted a marked deterioration in Ben's physical health in 2016. He was in and out of hospital as both an inpatient and an outpatient. He was required to attend various medical appointments. Ben needed a great deal of support to enable him to attend. Coordination of support fell to Adult Social Care as a single agency. Adult Social Care engaged health professionals such as dental, gastroenterology, mental health, and the Huntingdon's Disease Association. On reflection, Adult Social Care professionals said that they wanted to ensure that Ben had the necessary support to meet his health care needs but they found it difficult to navigate the multiple health pathways involved.

7.2.9 All agencies involved (including Adult Social Care) agreed that Adult Social Care had the lead coordinator role in Ben's care and support. That said, if Ben had been allocated a health professional to take a lead coordinator role in his care and support for example a Community Matron, he might have received a better co-ordinated health care management response and expertise in care planning for and with Ben. Consistency of support is important; however, in the case of people with complex needs there needs to be clear pathways or routes to services and communication between all key agencies involved is essential.

7.2.10 For over 10 years, Community Health and Social Care Teams have had established 'Core Group / Virtual Ward' in place. These meetings usually take place once a month and are coordinated by the local health and social care community team's coordinator. 'Core Group / Virtual Ward' provide a forum for health and social care professionals

across agencies to communicate about the most vulnerable people in their community and identify clear pathways for support. The focus of these groups has been traditionally on older people and people with physical needs. Of note is that Mental Health Services are not part of these groups. Whilst Ben was discussed at the local Core Group / Virtual Ward this did not alleviate the challenges in identifying the appropriate services required to support and work alongside Ben.

7.2.11 The need for multi-agency working with Ben is evident from this review. There were clearly challenges in getting a 'true' multi-agency response early on which meant the absence of a whole system approach in supporting Ben. When agencies are delivering care to people with complex long-term conditions, there should be multi-agency planning to ensure their needs are met.

Learning Point 4: *Advice and support needs to be easily accessible when someone has mental health needs where those needs do not meet the criteria for secondary Mental Health Services (secondary Mental Health Services are services which generally will need a referral from a GP e.g. hospitals and community mental health teams).*

Learning Point 5: *Multi-agency working is essential when supporting people with multiple health and social care needs. Consideration needs to be given to widening the remit and membership of Core Groups / Virtual Ward to include younger adults with complex health, social care and mental health needs.*

7.3 Risk Assessment and Risk Management

7.3.1 Throughout the time in scope, Ben threatened to, and did physically assault people. He had reported feelings of suicide and there had been incidents of risk to himself which included rough sleeping, accidents with cars and one fall from height which resulted in a RNLI beach rescue. There were ongoing concerns relating to medication management and whether Ben was inadvertently overdosing of medication.

7.3.2 Ben fell outside of a legal framework for care, beyond that which Ben would consent to for some time. Ben's mental capacity was considered by professionals involved in his care at various stages throughout their involvement. This was good practice. Decision-specific Mental Capacity Act assessments were completed, and the principles of the Mental Capacity Act were properly applied. Great care was taken in the decision-

making regarding Ben's capacity. He was consistently assessed as having capacity to make decisions.

7.3.3 The threshold for use of the Mental Health Act assessment was not met. Consideration was given to completing a Mental Health Act assessment on at least 3 occasions during the time in scope. On each occasion, it was felt that Ben was not presenting as requiring a Mental Health Act assessment and a psychiatric admission was not indicated.

7.3.4 Although Ben did not meet the legal criteria for application of the Mental Health Act, it was agreed by all that, given Ben's complex needs and associated risks, his care and support needed to be considered in a multi-disciplinary / multiagency forum. There appears to have been a difference of opinion across organisations around what are acceptable levels of risk for Ben. This might have been resolved had there been earlier multi-disciplinary working where the risks of Ben's lifestyle choices were properly shared and understood. In June 2017 the Consultant Psychiatrist and Approved Mental Health Practitioner determined that a professionals meeting was needed as a priority. However, it wasn't until August 2017 that a multi-agency risk management meeting was convened. There is insufficient information to explain why there was so much drift or what the risk assessment was that prompted this decision. Risk management meetings need to be held in a timely manner. There needs to be more regular use of multi-disciplinary risk management meetings with clear outcomes and actions attributed to all agencies. It should not have to get to a point of instigating safeguarding procedures to get a multi-disciplinary team response.

7.3.5 Communication is key to ensuring that the risk and the plans around such risks are understood by all. Some decisions made were not communicated to the wider team supporting Ben. Equally, concerns regarding the effectiveness of the support Ben was receiving were not shared. An example of this is the changes made to Ben's medication prescription in January 2018. Others involved in Ben's care had concerns regarding this decision, but this was not communicated to the GP practice. It would be reasonable to presume that Ben's daily care package provided a safety net in terms of safe medication management, however the effectiveness of the commissioned service was uncertain due to Ben's engagement with the support.

7.3.6 Professionals expressed disappointment that the GP could not attend the meetings held in June 2018 or August 2018. It was felt that this was a missed opportunity to discuss all the risks, both known and perceived, and to formulate a collaborative

approach for Ben. Many of the issues were linked to deteriorating health including the difficulty Ben had in managing his medication.

7.3.7 Arguably, Ben was not receiving the care and support that had been assessed as being needed to meet his needs. Ben's Care Agency was subcontracted under Devon County Council's 'Living Well At Home' Contract. Within the contract there is a requirement that *'When the Service User is not available or unwilling to receive the Service offered by the Subcontractor…The Subcontractor should record the details of the abortive visit and notify (Contractor) at the earliest opportunity or immediately where there is concern about the wellbeing of the Service User.'* Care Workers reported that Ben would go out 10 mins before they were due and would return 10 mins after they left. They would often see him out and about in the local area when they were due to visit. This raises a significant question regarding the value of the support, both in terms of adding value to Ben, but also in terms of the cost of providing a care package that was not being fully delivered. Care Workers failed to notify the Contractor of this. The fact that professionals held the view that Ben had capacity may have led to the normalising of certain behaviours. For example, the care agency had no protocol in place for when someone is not at home. It was, from the care workers' perspective, not unusual for Ben not to be at home when they visit or for days to pass without them seeing Ben even out and about in the local community. Ben was missing for 7 days without this being escalated. The lack of urgency surrounding the non-reporting of his absence is cause for concern, given that Ben was found dead shortly after his absence was reported.

Learning Point 6: *There needs to be more regular use of multi-disciplinary risk management meetings. The perception that multi-agency risk management can't occur unless under the auspices of undertaking a safeguarding enquiry or following through a safeguarding concern needs addressing. Risk management meetings need to be held in a timely manner.*

Learning Point 7: *In line with contractual requirements, Domiciliary Care Agencies need to have a clear protocol in place for when a person is not home and/or missing. In the event that the Service User is not available or unwilling to receive the Service this should be treated as urgent and reported immediately.*

7.3.8 Ben's Care Agency immediately took steps to amend their policy around reporting non-attendances following the lesson learnt from Ben's experience.

7.3.9 In late November 2018 Ben's Care Agency adopted and embedded the 'Herbert Protocol' into their care planning and client risk assessment process. The 'Herbert Protocol' is a national scheme that encourages Care Workers, family and friends to provide and put together useful information in one form, which can then be used in the event of a vulnerable person going missing. The form can be sent or handed to the police in the event of a person going missing, reducing the time to gather this information. Ben's Care Agency routinely, with their clients or representatives' consent, complete the form and store this electronically with uploaded photographs. A hard copy is also kept in a client's care plan at their home address, to be used in the event of the client going missing.

7.3.10 Ben's Care Agency carried out a review of their policy and procedures in February 2019. New processes represent a clear prescriptive procedure, aimed at eliminating any hesitancy or delays in taking follow up action, and in escalating concerns through to client's family members, local authorities and the police.

7.3.11 Changes were also made to their information system, to include specific work instructions for all Carer Workers visiting clients and placing additional requirements and responsibilities of office and on-call staff for recording information on client's case records. Since February 2019, office and on-call staff have actioned this process on 103 occasions, following reports from care workers that a client has been absent from home for their visit. On every occasion, the client has been located safe and well (or found to have been admitted to hospital) on the same day that the carer has reported the client to be absent from home.

7.4 Specialist Support in Devon for People with Huntington's disease.

7.4.1 The Huntington's Disease Association employs a Specialist Huntington's Disease Adviser who covers Cornwall and Devon. The Advisor gives support and advice to families and care workers and people with Huntington's Disease, as well as to health and care professionals. Support available through the Specialist Huntington's disease Adviser includes, but is not limited to: visiting people at home to assess the individual, give advice in relation to Huntington's disease and to provide emotional support; delivering a confidential telephone helpline service; signposting or referring to medical, health and social care professionals; and the specialist Huntington's Disease clinics; advocating for the person with Huntington's Disease to get the best support; organising

and attending local support networks and carers' group meetings and educating medical, health and social care professionals, meaning better diagnosis and ongoing care.

7.4.2 The Huntington's Disease Association keep a register of all people known to them in the Devon area (this will be an underestimate of the total population of people with Huntington's Disease). At the time of writing this report in Devon it is known that there are:

- 148 adults symptomatic with Huntington's disease (national population estimate is 1 in 10,000, so around 8,000 symptomatic people in the UK).
- At risk are 150 people (estimate is that there will be 4 people for every 1 person symptomatic).
- A further 20 people known to the association and not categorised.
- Carers number is 171 people
- This brings a total of 489 people accessing information, help and support from the Huntington's Disease Association in Devon currently.

7.4.3 The Huntington's Disease Association is a valuable support service. There should be a focus on promoting awareness and better use of the Huntington's Disease Association who can offer support to people living with Huntington's disease as well as to their carers.

8. Good Practice

8.1 Professionals who attended the Learning Event were asked to identify areas of good practice from their own and other agencies' involvement. Evidence of notable practice included:

- The 'virtual ward' approach facilitated regular multi-disciplinary team discussion.
- The risk management meeting in August 2017 was able to achieve a focus on outcomes and actions for Ben that were realistic.
- There was good communication from South West Ambulance Service NHS Foundation Trust to Ben's care agency and to the hospital to understand medication risks.
- NHS funding was eventually secured to support Ben to access health appointments; this included funding so that agency staff could go with him.

- There is substantial evidence of perseverance from adult social care staff & mental health staff to support Ben
- There was regular consideration and review of issue-specific capacity. Great care was taken in the decision-making regarding Ben's capacity around medication and the prescribing of his medication.

9. Conclusion

9.1 Huntington's Disease is a relentlessly progressive neurodegenerative disorder which, for Ben, resulted in complex care needs. These needs were met by many agencies. The difficulties Ben experienced as a result of his Huntington's Disease with related frontal lobe symptoms such as poor executive functioning, poor planning and organising, impacted on his ability to cope with daily life.

9.2 Given Ben's complex needs and associated risks, his care and support needed to be considered in a multi-agency and multi-disciplinary way. It is evident that professionals involved in Ben's care and treatment went to great lengths to offer support but the experience, skills and confidence of staff working with someone who has a complex long-term condition plays a big part in the success of such support.

9.3 Ben was reluctant to engage with services. Additionally, it is apparent that professionals had concerns that excessive intervention would exacerbate the risk which meant they focused on unobtrusive help and monitoring. Professionals struggled to work out what legal framework (if any) they could use to support Ben. He fell outside of a legal framework for care, beyond that which Ben would consent to for some time.

9.4 There is a general agreement from health and social care agencies who worked with Ben on the learning points arising from this review. Recommendations were made by the group based on the learning points identified. These will inform the overall multi-agency action plan.

10. Recommendations

1. Devon County Council to ensure that all Social Care Plans are informed by a strengths-based assessment which means considering different components that support or enable the individual (equally applied to the person and carers) to deal with challenges

in life in general and in meeting their own needs and achieving their desired goals **[Learning Point 1]**

2. Ensure that all health and social care professionals engage the support of condition-specific specialist services in their assessment and planning of care **[Learning Point 2]**

3. NHS Devon CCG to be cognisant of Huntington's Disease when undertaking the two areas of review in relation to commissioning arrangements **[Learning Point 3]**

4. Ensure health and social care professionals across commissioning and operations are conversant with the range of services available for people with a diagnosis of Huntington's Disease, what their criteria is, what their limitations are, and how the service can be accessed **[Learning Point 3]**

5. Devon Partnership Trust to share single point of contact details with Devon County Council to ensure staff know how to access advice and support from mental health services when someone has mental health needs which do not meet the criteria for secondary Mental Health Services. Not just a single point of contact for referral **[Learning Point 4]**

6. Devon County Council is in the process of reviewing 'Core Groups / Virtual Wards'. Consideration needs to be given to widening the remit and membership of Core Groups / Virtual Ward to include adults (under 65) with complex health, care and mental health needs **[Learning Point 5]**

7. Assurance that there are risk management procedures with clear actions and accountabilities in place and that staff are trained and supported to be competent when supporting individuals who pose high risks. Risk management meetings need to be held in a timely manner. Consideration of a review of agencies' own risk management procedures to strengthen consistency across health and social care. **[Learning Point 6]**

Helena Riggs, Safeguarding Adults Practice Lead
Devon Safeguarding Adults Partnership
September 2020

Appendix 1: NHS Devon CCG response to Mental Health Commissioning arrangements

Devon Safeguarding Adults Review (Huntington's)

NHS Devon CCG has the following services in place which may be able to support a person's mental health needs. The below would be dependent on a patient's presentation, stage and primary need / diagnosis.

Improving Access to Psychological Therapies

- Improving Access to Psychological Therapies (IAPT) may be able to support an individual with depression and anxiety in the earlier stages of Huntington's. This can be accessed via self-referral, GP or via long term condition clinics within acute trusts.

Community Mental Health (Adults)

The service includes assessment, formulation and treatment and covers a range of serious mental health diagnoses including:

- Moderate to severe depressive episodes and disorders
- Risk to self or others – Clear and persistent suicidal urges / plans, severe neglect
- Psychotic Disorders
- Debilitating anxiety disorders
- Severe Obsessional Compulsive Disorder (OCD)
- Eating disorders
- Significant PTSD
- Relapse of previous serious Mental Health difficulties
- Significant Personality Disorders and older person's mental health

Older People's Mental Health

Multidisciplinary clinical team with consultant psychiatrist, nursing, occupational therapy, psychology and pharmacy input. The team provides assessment, treatment and interventions to people with complex and enduring mental health problems. Older People's CMHT aims to:

- Provide a comprehensive assessment (including risk assessment) and diagnosis for people with both functional and organic mental health problems that are complex, enduring and impact significantly on their ability to remain well in their community or current place of residence.
- Offer advice and support to enable a mental health specific care/support plan to be developed
- Work in partnership with the individual and carer to identify needs to aid recovery and/or an increased sense of wellbeing
- Offer treatment options (including talking therapies) and provide care for people with complex and enduring mental health problems
- Support the local delivery of a care pathway that is flexible, holistic and responsive to the needs of the individual and their carers
- Support people with their physical health, when related to their mental health needs, and assist them to access appropriate support from relevant services
- Offer choice to increase a sense of wellness/recovery and social inclusion
- Provide education and support to primary care teams, social and community services, and other statutory, voluntary and independent sector organisation providing care to older adults with mental health problems.
- Support the prevention of admission to hospital by offering home visits and providing access to local community support.

For clients who are working age and older people with a diagnosis of Huntington's Disease and predominant Dementia type presentation, Older People's Mental Health may undertake

care co-ordination functions. However, this is based on individual patient need based on assessment. Due to the nature of Huntington's Disease broader service support is sought through multi-disciplinary team approaches with non-mental health services.

Psychology and Psychological Therapies
The unit delivers the following discrete services:

- Psychological interventions for adults including art based therapies
- Psychological interventions for people over the age of 65
- Health Psychology and Neuropsychology Services

Heath Psychology services have direct pathways with the Royal Devon and Exeter NHS Foundation Trust. In South Devon and Torbay Health Psychology services are provided by Torbay NHS Foundation Trust.

Diagnoses which may be supported by Psychological Therapies include acquired and congenital brain injuries, Dementia and degenerative neurological conditions.

Community physical health care
In South Devon the health care of people with long term physical health conditions is supported by local community health and wellbeing teams based in localities. The teams are responsible for meeting the health and wellbeing needs of the people living in their community and have a daily meeting where people in the locality who are most at risk of their health deteriorating are discussed. People from the locality who are already in Torbay or a community hospital bed are also discussed to see how the team can enable them to be discharged as soon as possible in a planned safe and supported way.
The health and wellbeing team includes:

- GPs
- Community matron
- Community nurses
- Occupational therapists,
- Physiotherapists
- Social workers,
- Social care coordinators
- Pharmacists
- Support workers from independent and voluntary sector organisations to help link people to their communities.

Community Neurological Rehabilitation Team
This is a community team of therapists working with people after a stroke or acquired brain injury and those with neurological conditions, provided by Torbay and South Devon Foundation Trust.
The team includes:

- Occupational Therapists who provide assessment, education and treatment; including cognitive and functional activities of daily living and returning to work. They also accept referrals for returning to driving and anxiety management.
- Physiotherapists who provide assessment, education and treatment including gait retraining and functional mobility, upper limb retraining, management of fatigue and management of motor impairment including weakness and/or spasticity.
- Speech and Language Therapists who provide assessment, education and treatment of communication difficulties (dysphasia), including reading & writing, and the assessment, education and treatment of swallowing difficulties (dysphagia).
- Assistant Practitioners/Rehab Support Workers, experienced in working with all the therapies and so can help people to work on several goals at the same time.
- They have links with the Clinical Neuro-Psychology Team.

Specialist Huntington's Disease Advisory Service
In addition to the above there is a "Specialist Huntington's Disease Advisory Service" commissioned. The primary purposes of this service are:

- To offer advice, information, training and support to people with Huntington's Disease (HD), at risk of HD and their carers, in order to improve quality of life and enable to people to remain as independent as possible.
- To work closely with statutory authorities and voluntary organisations to ensure a comprehensive, seamless service and to provide the best possible care for individuals and their carers. The Huntington's Disease Association is the only organisation offering this service both locally, regionally and nationally.

In response to your query, it is not felt there needs to be a review of NHS Devon CCG's commissioning structure arising from this case. However, there are two areas of review scheduled which will support future cases these are:

1. A review of smaller community-based contracts will be undertaken to ensure their specifications are up to date, meeting local need and supporting NHS long term plan ambitions. The Specialist Huntington's Disease Advisory Service will form part of this review.
2. Development of a new Community Mental Health Framework for adults and older adults with common mental health conditions and severe mental illness. The development of a new model is in line with NHS Long Term Plan Ambitions and national Community Mental Health Framework Guidance. National guidance requires greater integration with primary care and wider community-based services along with increased VCSE connectivity.