SAFEGUARDING ADULTS REVIEW (SAR)

Aidan
SAR Report

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Prepared for: **South Gloucestershire Safeguarding Adults Board**

This review is

> '*talking about ordinary people – carers and cared for – who find themselves in potentially extremely difficult situations that they didn't choose, with immense emotional and practical implications for their lives*.'[1]

(a quote from a carer who contributed to the LGA/ADASS briefing note on 'carers and safeguarding', 17/02/2022)

'*It is hard to feel safe if we don't feel in control of what is happening in our life and hard to feel in control if we don't feel safe.*'[2]

'*Let me decide and if I can't it's still about me!*'[3]
(a quote from an expert by experience, 2009)

'*Safeguarding is complex*'.
'*Sometimes there are no perfect answers: there are usually risks as well as benefits associated with all decisions. Adult carers are not a homogenous group. Their needs and circumstances are very diverse.*'[4]

'*Carers… may come to feel that it is "OK not being OK" when it is not and be left to get on with life.*'[5]

[1] https://www.local.gov.uk/parliament/briefings-and-responses/carers-and-safeguarding-briefing-people-who-work-carers
[2] ADASS Advice Note, *Safeguarding Adults 2011*, ADASS Safeguarding Policy Network April 2011
[3] Luton Borough Council / Safeguarding of Vulnerable Adults Board, Safeguarding Vulnerable Adults Conference 2009
[4] ADASS Advice Note, *Safeguarding Adults 2011*, ADASS Safeguarding Policy Network April 2011
[5] ADASS Advice Note, *Safeguarding Adults 2011*, ADASS Safeguarding Policy Network April 2011

The day service staff had opportunity to get to know Aidan well over a long period of time. His personality and charisma touched many hearts.

Understanding how Aidan communicated was important for him. We were able to meet his needs, offer choice, understand his feelings and emotions and his likes and dislikes.

Aidan had a passion for sports, from watching tennis on the iPad to going out on day trips to the pub to play snooker. Another passion for Aidan was music. He enjoyed listening to music and playing his maracas. He would shake the maracas for hours, which would bring smiles to staff faces as we knew this was a sign Aidan was happy.

Aidan would also show his like of staff and other service users by patting them on the head or engaging with eye contact.

This connection meant a lot to staff as we all felt we understood what Aidan wanted. Aidan is so very much missed by us all.

Sleep tight Aidan. 

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1. Introduction

1.1 Brief overview of the circumstances that led to this review

1.1.1 This Safeguarding Adults Review (SAR) is commissioned by the South Gloucestershire Safeguarding Adults Board (shortened hereafter to SGSAB) on the case of Aidan, following his death on 4/4/2024.

1.1.2 Aidan was a 61-year-old white British man. He had a learning disability and lived at home with his brother (referred to hereafter as adult A), who was his main carer. Aidan had another brother (referred to hereafter as adult B) who lived away from the family home and was involved in his welfare.

1.1.3 There had been significant safeguarding concerns for many years about his care at home and barriers to his access to health and social care.

1.1.4 Aidan died in Southmead Hospital ICU. The proposed cause of death was oesophageal rupture and acute kidney injury / chronic kidney disease.

1.1.5 There was an open safeguarding at the time of his death.

1.2 Statutory duty to conduct a Safeguarding Adults Review

1.2.1 The Care Act 2014 stipulates that a Safeguarding Adults Board (SAB) must arrange for a Safeguarding Adults Review (SAR)[6] where:

- an adult with care and support needs has died and the SAB knows or suspects that the death resulted from abuse or neglect, or an adult is still alive and the SAB knows or suspects that they have experienced serious abuse or neglect; and
- there is reasonable cause of concern about how the Board, its members or others worked together to safeguard the adult.

1.2.2 Board members must co-operate in and contribute to the review with a view to identifying the lessons to be learnt from the adult's case and applying those lessons to future cases[7].

1.2.3 A SAR is not an inquiry into how someone died or suffered injury, or to find out who is responsible. The purpose is not to allocate blame or responsibility[8].

1.2.4 SARs should reflect the 6 safeguarding principles[9] - empowerment, prevention, proportionality, protection, partnership and accountability.

[6] Sections 44(1)-(3), Care Act 2014
[7] Sections 44(5), Care Act 2014
[8] Para 14.168, Care and Support Statutory Guidance updated 18/02/2025
[9] Para 14.166, Care and Support Statutory Guidance updated 18/02/2025

1.3 SGSAB's decision to conduct a review

1.3.1 The South Gloucestershire SAR subgroup identified there would be learning from what happened to Aidan and the rapid review of agency case files identified that the criteria to undertake a SAR had been met.

1.3.2 A recommendation was subsequently made to the SGSAB chair to undertake a SAR. This was agreed and the process for the SAR commenced in September 2024.

1.4 The lead reviewer

1.4.1 Annie Ho is a registered social worker and is the independent lead reviewer of this SAR.

1.4.2 Annie has had many years of practice and senior management experience in local authority safeguarding adults and mental capacity work. She provides expert reports to the court in her role as an independent social worker, alongside her SAR work. Her direct engagement with vulnerable adults and their families continues to inform her work as an independent reviewer.

1.5 SAR Review Group membership and Terms of Reference for this review

1.5.1 At the first SAR Review Group meeting of 21/11/2024, membership of the SAR panel and the ToR of this SAR were agreed. The ToR was reviewed throughout the SAR process.

1.5.2 The membership of the Review Group includes representation from relevant agencies relating to their senior management responsibility in decision making and oversight of quality assurance of the review, independent of operational responsibility in the case.

1.5.2.1 South Gloucestershire Adult Social Care (ASC)

1.5.2.2 Sirona care & health

1.5.2.3 Design 4 Life Day Centre

1.5.2.4 NHS Bristol, North Somerset and South Gloucestershire ICB: on behalf of GP / Primary Care

1.5.2.5 North Bristol Trust (NBT): Southmead Hospital

1.5.2.6 South Western Ambulance Service NHS Foundation Trust (SWASFT)

1.5.2.7 Advocacy: VoiceAbility

2. Review Methodology

2.1 Communication with Aidan's family

2.1.1 Family engagement, if possible, is key to a Safeguarding Adults Review.

2.1.2 Attempts were made by the SAB business manager and the reviewer to make contact with Aidan's brothers by telephone calls and emails, but no responses were received.

2.1.3 The reviewer later called adult B, who requested in response for a three-way telephone conversation. The reviewer spoke to the brothers on the phone on 7/2/2025.

2.2 Relevant partners were asked to complete Agency Case Information forms before the reviewer was appointed.

2.3 With the agreement of the ToR at the first Review Group meeting of 21/11/2024, group members were asked to complete agency-specific Critical Analysis (CA) forms. This approach is aimed at promoting Review Group members' ownership through their contribution to shared analysis and learning, adopting a peer challenge perspective without over-reliance on the expertise of the individual reviewer.

2.4 The CA forms are designed to aid proportionate and smart analysis by individual agencies of their involvement with Aidan. The important focus is on the context for practice at a single agency level, why particular actions were undertaken and decisions made.

2.5 The agency-specific CA form aligns with the SAR Quality Markers[10]. SAR Quality Markers are a tool to support people involved in commissioning, conducting and quality-assuring SARs to know what a good SAR looks like.

2.6 Three SAR Quality Markers are specifically referenced and highlighted for the attention of the Review Group members and practitioners and managers. These include QM9 on assembling information, QM10 on practitioner's involvement and QM12 on analysis.

2.7 The reviewer offered one-to-one and group reflection meetings to key staff members of relevant agencies who were involved in the care of Aidan. These helped to provide insight to the reviewer of the challenges individuals / agencies faced in working on this complex case, and the learning they have taken to inform their continuing practice in safeguarding adults.

2.8 A practitioners learning workshop (stage 1 Learning Event[11]) was led by the reviewer on 11/02/2025, where practitioners of all agencies were invited to share with each other their reflection and learning from this case, and their analysis of what needs to change, what changes have already been put in place and what agencies can do to create further change. Participants were invited to adopt a peer challenge perspective and to share and extend their learning to a multi-agency level.

2.9 '*It is vital, if organisations are to be able to learn lessons from the past, that reviews are trusted and safe experiences that encourage honesty,*

[10] https://www.scie.org.uk/safeguarding/adults/reviews/quality-markers

[11] https://www.researchinpractice.org.uk/media/hpsba3z3/developing-effective-safeguarding-adult-review-learning-events_pt_web.pdf

transparency and sharing of information to obtain maximum benefit from them.'[12]

2.10 An independent advocate represented Aidan throughout the session. This was aimed at putting Aidan at the centre of the learning, and enabling his voice to be heard.

2.11 Interactive tools were used to gauge different agency representatives' level of understanding and knowledge of the SAR process, professional curiosity, legal literacy including mental capacity considerations and best interests decisions, the statutory safeguarding framework and partnership working.

2.12 The overall review methodology is aimed at developing a working relationship of trust with all partners and prompting an open learning culture.

2.13 To focus on learning, the review acknowledges that organisational and systemic factors can cause incidents.[13]

2.14 The alignment of practice perspectives with a systems approach enables the identification of enablers and barriers to good practice as well as systemic risks in the wider partnership.[14][15]

3. Review Scope

3.1 The review focuses on events in the twelve months prior to Aidan's death in April 2024.

3.2 The reviewer invited the Review Group members to include in the completion of their agency-specific CA forms, pertinent information outside of this timeframe, with particular consideration of the triggers for adult A's (and adult B's to a less extent) increasing disengagement from professionals and services, covering the Covid pandemic, Aidan's hospital admissions for acute care and his decline in physical health.

3.3 D4L, Sirona and the GP shared information on safeguarding concerns they held over a long period of time before the start of the review period.

[12] Para 14.140, Care and Support Statutory Guidance updated 18/02/2025
[13] Safeguarding Adults Reviews under the Care Act: implementation support, SCIE March 2015 https://www.scie.org.uk/files/safeguarding/adults/reviews/care-act/safeguarding-adults-reviews-under-the-care-act-implementation-support.pdf
[14] Animation for strategic leads participating in case reviews https://biteable.com/watch/3872657/7b11f70eb5409fcb5e681015575e7027
[15] Animation for practitioners participating in case reviews https://biteable.com/watch/3867279/1296334c0b8ddeda1e2c48c9f8dc6e05

4. Aidan: the person

4.1 The reviewer gathered information about Aidan from professionals and, in particular, representatives of D4L who had known him for a long time.

4.2 Aidan had complex health needs with congenital cerebral palsy and microcephalus (a condition in which a baby's head is much smaller than expected for the baby's age, this can be due to the brain not developing properly either during pregnancy or after birth and can be linked to physical disabilities and learning disabilities) and epilepsy diagnosed in childhood. He had severe reflux oesophagitis and dysphagia. He was reported to have a visual impairment.

4.3 Aidan lived in his family home. He was cared for by his parents until they passed away, when adult A took over full-time care of Aidan. Adult B moved away from the family home some years ago and continued to maintain contact.

4.4 Aidan was the eldest of the three brothers. Both adult A and adult B were involved in his care from the time when their parents were caring for him.

4.5 D4L representatives referred to the '*good life*' Aidan's parents provided for him. He enjoyed his holidays and good attendance of services. His mother was '*very dominant*' and '*treated him very much a like a child*'.

4.6 All professionals hold the view that Aidan enjoyed a special relationship with his two brothers. This was clear from his smiles and positive responses to them.

4.7 Aidan enjoyed attending the day centre and was fond of the staff who worked with him.

4.8 Aidan had '*a wicked sense of humour*'. He would look at himself in the mirror and laughed at himself. He was a '*people watcher*' and found other people's mishap funny.

4.9 D4L described Aidan as a '*social character*'. '*He craved contact with other people.*' When he saw a member of staff he liked, he would reach out to connect with them.

4.10 D4L's communication passport highlighted that how Aidan communicated was really important to him and to staff supporting him. Staff used communication objects and pictures to promote his choice. An 'objects of reference programme' for Aidan was in place, which provided consistency of linking different objects to specific activities.

4.11 Aidan was able to communicate clearly what he wanted to say. He would push people away if he didn't want to be with them; he would put his hand out to indicate he was not enjoying something or he did not want it anymore. He would smile and touch an object to indicate his choice.

4.12 Aidan would display self-harming behaviours, e.g. biting his hand, when he felt he was rushed and not understood.

4.13 Aidan enjoyed watching sports on his iPad, including snooker, tennis and cricket. He liked playing snooker and watching other people play snooker at the pub. He also enjoyed his trips to bowling; he sometimes touched and pushed the ball.

4.14 Aidan enjoyed music. He carried with him a little radio and musical instruments in his bag.

4.15 Feeding was always a difficulty for Aidan. It required a lot of patience and encouragement. His communication passport referred to 'trapped wind' he suffered from, which was painful for him.

4.16 D4L described that their care became very much about eating and drinking towards the end of his life. They believed that his health deteriorated since the Covid pandemic. The focus became very much about his health needs and less on his social care needs. They explained that his needs with regards to connection with the community could only be met on a good day.

5. Review Focus

The specific areas of enquiry requiring critical analysis include the following.

5.1 The voice of the person – working with an adult at risk who has limited communication and lacks mental capacity for care and support decisions; appropriate representation including applying the statutory duty of advocacy

5.2 The voice of the family / carer – working in partnership with the family / carer of an adult at risk

5.3 The consistency of the care provided by all organisations and professionals with expected standards in line with primary legislation, statutory guidance and codes of practice, and relevant policies and procedures including:

5.3.1 Care Act 2014 – consideration of wellbeing outcomes and holistic assessment connecting mental health and physical health

5.3.2 Mental Capacity Act 2005 – mental capacity considerations and assessment, application of the statutory principles in practice and best interests decision-making, including substitute decision-making authority

5.3.3 Safeguarding Adults, application of statutory principles and Making Safeguarding Personal

5.4 Safe care at home

5.5 Inter-agency communication and information sharing and escalation, and multi-agency partnership work including shared risk assessment, management of harm and shared decision making

5.6 The understanding and application of professional curiosity

6. Key Lines of Enquiry

6.1 How was Aidan voice sought from him and recorded by and shared amongst professionals?

6.2 What could we identify as abuse and/or neglect of Aidan?

6.3 What were the opportunities for professionals to work more effectively together to prevent and protect Aidan from harm? What were the barriers to this happening?

6.4 What were the complex relationship dynamics between the cared for, the carer(s) and the professionals?

6.5 What could the application of Making Safeguarding Personal look like for Aidan?

7. Thematic Analysis

The key themes here are taken from section 5. The themes are grouped to provide a helpful critical analysis and to inform recommendations from this review.

7.1 **The voice of the person** – working with an adult at risk who has limited communication and lacks mental capacity for care and support decisions; appropriate representation including applying the statutory duty of advocacy

7.1.1 The reviewer observed from all professionals a strong sense of person-centred care. However, the decisions and actions were very much determined with Aidan in the centre together with adult A, due to the particular circumstances of the care arrangements at home.

7.1.2 The contribution of D4L in their Critical Analysis form, reflection meeting and the multi-agency learning workshop, provides an example of good practice in person-led care. There is clear evidence in their practice as well as in their records, a commitment to promote Aidan's choice and control in daily decisions including food and activities, and his overall wellbeing and wider autonomy.

7.1.3 The documentation of D4L, including their communication passport, objects of reference programme, care plan, eating and drinking risk assessment and manual handling and personal care risk assessment, were written in the first person of Aidan. These reflected their relational and rights-based approach in their work with Aidan.

7.1.4 The long history and the changeable level of adult A's engagement with services and latterly the complete disconnection with professionals, should have raised questions about the 'real voice' of Aidan, hidden behind what adult A presented to professionals.

7.1.5 It is important to distinguish between a person-centred approach which all professionals in this case attempted to promote, and a person-led approach which D4L staff and particular Sirona practitioners adopted. (see 7.1.14.2)

7.1.6 In order to keep communication channels open with adult A, it appears that ASC practitioners and the GP maintained a less intrusive approach. For example, anti-biotics were prescribed for Aidan on demand from adult A.

7.1.7 Over time, what professionals considered as a more balanced and more proportionate approach, resulted in less face-to-face contact with Aidan and direct observations of his living conditions and care arrangements at home.

7.1.8 Different community nurses had limited access to visiting Aidan at home and it was not possible for them to form a bigger picture of the circumstances in the home environment, particularly because details of relevant safeguarding concerns were not shared with them.

7.1.9 The ICB shared that Aidan was never coded as having a learning disability and, as a result, was not offered routine learning disability reviews by the GP. Aidan, together with adult A as his carer, could have benefitted from a 'reasonable adjustment flag' on the GP recording system.

7.1.10 At the learning workshop, practitioners were invited to reflect on what they could have done differently in enabling the voice of Aidan to be heard, how they could have sought his voice directly from him and noting it in their recording and assessments. Their responses included meeting with him in person, referring to his communication passport, providing choices and offering advocacy.

7.1.11 Review of records showed the involvement for a short period in 2017 of advocacy in Care Act review. This was followed by a significant gap of six years when Aidan was not represented by an advocate, presumably because it was believed that he was being appropriately represented by his family. Advocacy referrals were made in 2023 for decisions relating to discharge planning, Care Act assessment and safeguarding, but were later closed due to communication issues (reasons unclear from minimal recording details) between the advocacy provider and ASC.

7.1.12 Practitioners also shared the learning they had gained from the contribution of the independent advocate, who represented the voice of Aidan at the learning workshop. Non-instructed advocacy would have provided added value to this complex case.

7.1.13 The advocate shared at the workshop that had Aidan's voice been louder and clearer, perhaps there could have been a different outcome for him. It might be that the decision would have been made for him to stay where he was, but different options of care arrangements would

have been more clearly considered and determined with him at the centre of all decision making.

7.1.14 Reflection and learning on the voice of the person

7.1.14.1 Those who worked with Aidan were (rightly) focused on tasks including essential observations and assessments, due to his disability and complex health condition as well as the challenges for them in working with adult A.

7.1.14.2 Learning from this case highlights the importance of shifting from a professional task-focused approach to a more person-led approach, despite a person's significant disability and lack of mental capacity and ability to represent themselves. It is important for professionals to look beyond test results and observation scores, and to explore the wider picture directly with Aidan.

7.1.14.3 The reflection meetings highlighted the confusion around professional access to Aidan's communication passport. Although D4L held a detailed communication passport for Aidan, it did not appear that all professionals referred to it. Panel members advised that access could have been aided by the passport being uploaded by health and social care professionals on the 'Connecting Care' platform, and updated versions to be shared to keep it contemporaneous.

7.1.14.4 D4L managers shared that adult A made it clear he did not want them to share any information with the GP. Adult A also did not want the GP to share information with D4L and ASC.

7.1.14.5 Multi-agency information sharing under the statutory safeguarding framework should have been considered on a need-to- know basis. (see 7.7)

7.1.14.6 It is reliant on the family member to take the communication passport to the hospital on admission. This appears to be a precarious arrangement, considering in particular that Aidan was unable to represent himself.

7.1.14.7 There is a need to consider and put in place robust measures to ensure easy access of all relevant professionals to important documents about the communication needs and wider wellbeing of people with learning disabilities.

7.1.14.8 This informs recommendation 1.

7.1.14.9 There were missed opportunities to offer consistent advocacy support to Aidan. There were complex relationship dynamics in the circle of support for Aidan, including his brothers and numerous professionals. It was questionable that Aidan had appropriate representation during different professional interventions.

7.1.14.10 Adult A's ability to advocate for Aidan should have been respectfully questioned and the statutory duty of advocacy followed by professionals, long before the situation deteriorated and reached a deadlock.

7.1.14.11 The advocacy representative of the Review Group shared from her review of relevant records that there were gaps in communication between advocacy and the local authority. Social workers, at referral stage, should be clear about why family members are not appropriate to consult, so advocates can prioritise the case. There is also a learning point around the advocacy provider supporting social workers to understand the important role of advocacy. There is scope to foster better working relationships between professionals and advocates, in supporting adults at risk.

7.1.14.12 Adult A could have limited access for Aidan to an independent advocate, considering his pattern of declining professional intervention. Regardless of adult A's likely response, Aidan's right to advocacy should have been respected and a continuing attempt made to introduce an independent perspective to the difficult circumstances which he found himself in and which he did not have choice and control over.

7.1.14.13 The offer and introduction of an advocate who is completely independent of statutory services could have addressed the power imbalance between professionals with designated authority and the family carer. It may have provided an opportunity to shift the difficult family dynamics and helped to ease Aidan's (and adult A's) increasing sense of isolation.

7.1.14.14 It is clear that adult A had significant difficulties with communicating and engaging with formal services. His reactive response to professional questions and safeguarding concerns was to dismiss the concern and the individual. He could have found an independent advocate less threatening to his position. The advocate could have worked with Aidan outside of the home, at D4L, out in the community and in hospital, and provided meaningful representation of his voice.

7.1.14.15 There could have been opportunities for an advocate to give the time and propose creative options of supporting Aidan alongside the involvement of his brothers.

7.1.14.16 It is statutory duty under the Care Act for an adult at risk to have the support and representation of an appropriate person during care and support processes '*for the purpose of facilitating an individual's involvement*'[16] and in safeguarding processes. If

[16] Section 67-68, Care Act 2014

appropriate representation by their family is limited, advocacy should be offered.

7.1.14.17 Independent Advocates support people to be fully involved in a local authority assessment, care and support planning, care review or safeguarding process. Professionals need to know the broader duty to provide independent advocacy under the Care Act.[17]

7.1.14.18 Non-instructed advocates can act as the voice of the adult, making sure that their wishes, views and beliefs are represented and their rights are secured.

7.1.14.19 This informs recommendations 2 and 4.

7.2 **The voice of the family** – working in partnership with the family / carer of an adult at risk

7.2.1 It was clear to all professionals involved that Aidan's brothers were important people to him, and they enjoyed a very special relationship.

7.2.2 The brothers shared keeping watch over Aidan throughout his hospital stays. Hospital staff observed their attention to Aidan's care and Aidan's positive reactions to the care they provided for him.

7.2.3 There is evidence of good practice in the work of hospital staff and consultants in managing the conflict between the brothers' views with respect and compassion and offering clarity about treatment decisions to aid the family's understanding.

7.2.4 There is also evidence of good practice by D4L staff in supporting adult A in his care of Aidan during the Covid lockdown period. They offered to collect medication and do shopping. Adult A accepted support with shopping, which D4L staff bought and delivered to the doorstep. They made consistent attempts to ensure communication channels with Aidan and adult A were not shut down. They tried to initiate FaceTime calls during Covid so that Aidan could participate in remote sessions, but adult A did not feel they were beneficial for Aidan.

7.2.5 Records indicated the complex relationship dynamics between the brothers. Adult B raised concerns in the past with professionals about the food and condition in the bungalow, and about the pressures and impact on adult A of caring for Aidan. It appears that adult A denied to adult B that he refused access by professionals.

7.2.6 Records highlighted that adult A '*dedicated his life to caring for Aidan in the family home*'. Professionals described this as '*admirable*' of adult A. They believed that adult A was Aidan's '*expert*'; he '*intuitively knew Aidan's needs*' and he '*read Aidan well*'. Adult B pointed out to the reviewer that adult A was doing over 90% of the care.

[17] Para 7.64, *Care and Support Statutory Guidance* updated 18/02/2025

7.2.7 Adult A was recorded by the GP as Aidan's 'next of kin'. His role in making decisions for Aidan was not explored or questioned.

7.2.8 Professionals agreed about adult A's rigid way of thinking. D4L managers shared that adult A's perceptions of Aidan's needs never changed. This was confirmed in the reviewer's telephone conversation with the brothers. They were very clear that Aidan's health and social care needs remained the same and did not deteriorate with age or multiple hospital admissions.

7.2.9 Sirona practitioners pointed out the cyclical pattern of Aidan's chest infections and weight loss. Historically he had always bounced back. It was clear that his brothers did not share the view that Aidan's health continued to decline over time following repeated episodes.

7.2.10 ASC reflected in their critical analysis that their records appeared to reinforce this view that Aidan's care needs and wellbeing remained the same for many years. They highlighted that there was no reference in recording to Aidan being in good health or looking well, indicating a lack of offer of new opportunities and enhancement of his quality of life over a prolonged period. It seemed to have been '*accepted that his living arrangements were good enough*'.

7.2.11 The long telephone conversation the reviewer had with the brothers provided an insight into the numerous challenging conversations health and social care staff had with them, which must have resulted in professional fatigue. It is recognised that they persisted and kept going back despite being turned away.

7.2.12 Although the offer of a carer's assessment and other resources (e.g. respite and community meals) was declined by adult A, this should have triggered concerns about the wellbeing of adult A as the main carer and the long-term sustainability of the increasingly fragile situation.

7.2.13 In the reviewer's telephone conversation with Aidan's brothers, they both acknowledged they were '*very tired*' and '*respite care would have been very helpful*'.

7.2.14 This appears to have been the only area which the brothers shared with the reviewer that they would have liked professionals to do differently. However, professional experience indicated the contrary.

7.2.15 Sirona and hospital staff had brief glimpses when the brothers were tired from caring for Aidan, but they changed their mind when support was offered to them.

7.2.16 It may have been possible for staff of the local carers organisation, independent of social and health care, to open up conversations with adult A about the ongoing demands of caring, his mental and physical health and other relationships.

7.2.17 Both adult A and adult B made it clear to the reviewer that they did not trust professionals and their intervention was a hindrance. They could have been more open to advice and support from someone independent of statutory services.

7.2.18 Records indicated some kind of a compromise in the care and treatment arrangements for Aidan, with the primary aim of maintaining communication and some kind of relationship (though limited) with adult A and promoting the right to private and family life.

7.2.19 Reflection and learning on partnership work with the family

7.2.19.1 It appears to the reviewer that professionals continued to respect (rightly) the right of Aidan to private and family life, although it should be highlighted that Article 8 right is qualified and not absolute.[18][19]

7.2.19.2 Article 2 right to life and Article 5 right to liberty and security are limited rights. They can only be restricted in explicit and finite circumstances.[20] These could have been further explored and applied in this case.

7.2.19.3 Research by Carers UK highlighted the additional stress and risks the Covid pandemic posed for family carers, including deteriorating mental and physical health and increasing exhaustion and social isolation.[21]

7.2.19.4 The potential of Family Group Conferencing (FGC) and other options of mediation with the family could have been explored with Aidan as the person at the centre of decision making, supported by an experienced FGC coordinator and independent advocate.

7.2.19.5 FGC may be beneficial where someone has care and support needs and where families/support circles need to talk together about problems or concerns and find solutions.[22]

7.2.19.6 There are examples from other Councils of areas of good practice in the application of FGC in working with adults, which would provide learning for this case.[23] [24]

7.2.19.7 This informs recommendations 3, 4 and 5.

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[18] https://www.legislation.gov.uk/ukpga/1998/42/schedule/1/part/I/chapter/7

[19] https://www.equalityhumanrights.com/human-rights/human-rights-act/article-8-respect-your-private-and-family-life

[20] https://www.local.gov.uk/sites/default/files/documents/Practice_Tool_8_Providing information about the Human Rights Act WEB.pdf

[21] https://www.carersuk.org/news-and-campaigns/our-campaigns/our-previous-campaigns/caring-behind-closed-doors/

[22] https://www.researchinpractice.org.uk/adults/publications/2017/june/what-is-a-family-group-conference-for-adults-brief-guide-2017/

[23] https://fgcforadults.org.uk/

[24] https://www.scie.org.uk/news/opinions/family-group-conferencing

7.3 Care Act 2014 – consideration of wellbeing outcomes and holistic assessment connecting physical health and wider wellbeing

7.3.1 There were good reasons for the focus of professional interventions on Aidan's physical health and complex medical conditions, especially in his later years.

7.3.2 There were continuing and increasing concerns with Aidan's weight, nutrition, eating and drinking, risks of aspiration and constipation, moving and handling, impact on posture and skin integrity from increased time spent in his wheelchair and bed, non-attendance at D4L and therefore risk of social isolation.

7.3.3 There were missed opportunities of understanding what was really going on for Aidan and adult A and adult B, at a much earlier point when full-time care arrangements at home changed significantly after the death of their parents. Holistic assessments including conversations about choices and options under advance care planning and additional support for Aidan as well as for adult A, could have been undertaken before the situation became unsustainable.

7.3.4 It was acknowledged that Aidan was not recorded in the GP system as someone with a learning disability, and he therefore missed out on annual health checks and health action plans. These would have provided the opportunity to involve Aidan and adult A in conversations and yearly review of his health and wellbeing and any resulting recommendations of outcomes and actions.

7.3.5 Reflection and learning on holistic assessment connecting physical and wider wellbeing

7.3.5.1 It is clear for a long time that many of the well-being outcomes under section 1(2) Care Act were not being fully met for Aidan. These include:

(a) personal dignity (including treatment of the individual with respect);

(b) physical and mental health and emotional well-being;

(c) protection from abuse and neglect;

(d) control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided);

(e) participation in work, education, training or recreation;

(f) social and economic well-being;

(g) domestic, family and personal relationships;

(h) suitability of living accommodation;

(i)the individual's contribution to society.[25]

7.3.5.2 Recommendations from the national SAR analysis highlight '*the importance of holistic assessments, including risk and mental capacity, followed by detailed care planning that… gives parity of esteem to mental health and physical health needs*'.[26]

7.3.5.3 This is analysed further in sections 7.4 and 7.7.

7.3.5.4 The missed opportunities of annual health checks and health action plans, and the access of professionals to communication passport for people with learning disabilities, inform recommendation 1.

7.4 Mental Capacity considerations and best interests decision-making

7.4.1 '*The person making the determination must …so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.*'[27]

7.4.2 '*He must consider, so far as is reasonably ascertainable –*

(a) the person's past and present wishes and feelings…

(b) the beliefs and values that would be likely to influence his decision if he had capacity, and

(c) the other factors that he would be likely to consider if he were able to do so.'[28]

7.4.3 It is reasonable to assume that Aidan, having been cared for by his family and lived in his family home all his life, had strong beliefs and values in family relationships and the concept of home.

7.4.4 It is more challenging and, perhaps, more important to consider his past and present wishes and feelings, considering his extreme vulnerability due to his disability and lack of capacity.

7.4.5 The independent advocate facilitated the reflection of practitioners at the learning workshop about Aidan's wishes and feelings. It is also reasonable to assume that Aidan wished to feel safe, to be connected with his family as well as people outside his home, to feel free from pain and to live a long life.

7.4.6 '*Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.*'[29]

[25] https://www.legislation.gov.uk/ukpga/2014/23/section/1/enacted

[26] https://www.local.gov.uk/publications/analysis-safeguarding-adult-reviews-april-2017-march-2019

[27] Sec 4(4) MCA 2005

[28] Sec 4(6) MCA 2005

[29] Sec 1(6) MCA 2005

7.4.7 '*An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.*'[30]

7.4.8 In their reflection meeting, ASC practitioners acknowledged that although they knew Aidan lacked mental capacity for decisions relating to his care and support needs, they should have been more pro-active in applying the statutory best interests framework to all relevant decisions.

7.4.9 The Physiotherapist shared that adult A declined assessment at home and Aidan did not receive the postural assessment he would have been entitled to. Over time, there was increasing concern that he was kept in bed for long periods of time.

7.4.10 The Speech and Language Therapist (SALT) shared examples to illustrate the difficulties they had in addressing with adult A feeding and swallowing difficulties Aidan had. Although the SALT recommendation was level 6 diet for Aidan, adult A made the case for continuing with level 7 diet whilst making changes, e.g. offering crumbled crackers with drink, and sausage rolls with sauce. The SALT shared that Aidan could '*tolerate*' level 6 if he was well.[31]

7.4.11 The SALT added that a professional discussion would normally take place with the family carer around feeding risks, whereby a person's quality of life and comfort may have been chosen over eating and drinking a modified diet. It was not possible for them to have a meaningful conversation with adult A about this.

7.4.12 Most of the therapists visited and assessed Aidan at D4L as they were unable to gain access to his home. It was not possible for them to form a clear view about the home situation. There was evidence of unopened boxes of nutritional supplements at home.

7.4.13 It appears to the reviewer that some professionals felt they had to accept some kind of compromise and it was '*good enough*'. As Aidan's physical health condition continued to decline, the multi-agency group should have robustly applied the best interests framework and concluded that compromised arrangements were not in his best interests. The use of the safeguarding framework alongside the best interests framework could have formalised decision making.

7.4.14 There should have been more than enough surrounding evidence over time to suggest that less restrictive options in maintaining his care arrangements at home and further delay in making changes was no longer in Aidan's best interests.

7.4.15 Reflection and learning on considerations of mental capacity and best interests decision-making

[30] Sec 1(5) MCA 2005

[31] https://www.iddsi.org/standards/framework

7.4.15.1 It is clear to the reviewer that all professionals were focused on the best interests of Aidan. However, they relied disproportionately on the expressed views of adult A (and adult B to some extent) in their determination.

7.4.15.2 The formal best interests decision-making framework should have been established and made transparent to Aidan's brothers at the start of professional intervention, considering there was never any doubt that he lacked mental capacity for making his own care and treatment decisions. This would have provided clarification and open communication with his family that there was no substitute decision-making authority for his health and welfare and financial matters.

7.4.15.3 The GP records revealed their urgent referral in 2016 for an Oesophago Gastro Duodenoscopy (OGD / gold standard – a camera test to look at the food pipe and stomach) was made due to Aidan's swallowing difficulty and weight loss. Adult A's refusal of OGD on Aidan's behalf was not questioned or challenged.

7.4.15.4 In their critical analysis, the ICB shared their reflection that an OGD could have offered diagnosis and treatment of the underlying difficulty of swallowing and risk of aspiration for Aidan which was impacting on his day-to-day life. They highlighted that his death was related to oesophageal rupture – an OGD at an earlier stage could have provided an opportunity to investigate and treat the cause of this.

7.4.15.5 The GP recorded their suggestion for a referral in 2017 to the gastroenterologist as advised by the Speech and Language Therapist (SALT), but adult A stated that he felt it was unnecessary and declined this. The reassurances of adult A were again taken at face value.

7.4.15.6 The ICB concluded in their critical analysis that the views of adult A were prioritised over professional opinion. Aidan's general health continued to deteriorate, and he had admissions to hospital for infections and acute kidney injury, leading to a diagnosis of chronic kidney disease stage 3 in 2018.

7.4.15.7 The ICB reflected on the issue of diagnostic overshadowing, where the GPs could have assumed that Aidan's complaint was due to his disability, rather than fully exploring the cause of his symptoms. This subconscious bias made it harder to for clinicians to assess the presenting clinical risk to him.

7.4.15.8 The ICB also reflected on the lack of continuity in Aidan's care leading to '*no single practitioner having an overarching picture of who he was, his unique problems and complexities'*.

7.4.15.9 Standard authorisations issued under the Deprivation of Liberty Safeguards (DoLS) during Aidan's hospital admissions would have provided clear evidence that the no refusals requirement for DoLS was met, i.e. his brothers did not hold relevant powers of attorneys or deputies for health and welfare decisions for him.

7.4.15.10 The involvement of and consultation with adult A and adult B would then come under one of many considerations in the best interests checklist.

7.4.15.11 ASC's care plan of 2017 made it clear that Aidan lacked mental capacity for decisions relating to his care and therefore all arrangements were to be made under the best interests process involving all relevant people.

7.4.15.12 Basing their discussion and actions firmly on the legal framework of best interests, escalating concerns should have been addressed by the continuing appropriate representation of Aidan by an independent advocate in any best interests decisions.

7.4.15.13 Engagement with Aidan through the important role of an advocate who was experienced in non-instructed advocacy, would have contributed to the important consideration of his wishes and feelings by decision makers, including an advance care plan and contingency planning in his best interests.

7.4.15.14 For extremely vulnerable adults such as Aidan, there is a need for considering the benefits of incorporating '*keeping safe*' plans within support planning.[32]

7.4.15.15 This informs recommendation 6.

7.5 Safeguarding Adults and Making Safeguarding Personal – applying the statutory principles and the statutory framework of Safeguarding

7.5.1 Individual services and professionals demonstrated good practice in working with Aidan alongside adult A and adult B. However, the challenges presented by adult A continued to take away the primary focus from the best interests of Aidan and from making safeguarding personal for him.

7.5.2 There was a lack of an overall multi-agency strategy for managing and overseeing the repeated safeguarding concerns which were raised and closed.

7.5.3 D4L staff and community nurses, who appeared to have relatively more access to Aidan and adult A, were asked to continue to provide updates to ASC.

7.5.4 D4L managers shared they were asked to continue to make regular calls to adult A, even though they knew and repeatedly highlighted to ASC

[32] ADASS Advice Note, *Safeguarding Adults 2011*, ADASS Safeguarding Policy Network April 2011

safeguarding that they were not getting a true picture of Aidan from adult A. They made safeguarding referrals and escalated their concerns, but they felt nothing moved forward and there was no meaningful change.

7.5.5 Community nurse visits were undertaken on a rota basis. They were also asked to provide updates to ASC, but individual nurses shared they were not aware of the questionable reliability of information given by adult A and they were not provided with information about the wider safeguarding picture.

7.5.6 The increasing concern about further risks of harm to Aidan from adult A not progressing with referrals made on his behalf, and not allowing access by professionals, could have been brought at an earlier time under the statutory safeguarding framework with the local authority leading the decision and maintaining oversight.

7.5.7 The safeguarding process should have added value in this case as it is a statutory duty. When the risks are very high, safeguarding referrals should be made and progressed, unless clear plans are already in place and there is evidence of risks being effectively addressed and reduced.

7.5.8 Repeated safeguarding concerns were raised over many years regarding adult A's withdrawal of Aidan from services including respite and D4L, refusal of access to the home and assessment of Aidan following referral, weight loss, similar circumstances around repeated hospital admissions, and professional advice not being followed. Similar decisions and actions were agreed at multi-agency meetings, with no clear determination on how risks were to be mitigated.

7.5.9 The measure of the potential risks of harm to Aidan was based on visible evidence and readings, without critically analysing the underlying concerns. For example, the brothers' way of transfer and manual handling was not ideal, but accepted, as there was '*no history of unexplained bruising and/or injury re transfers*'.

7.5.10 It appears from the records that the analysis of risks was focused on face-value information of the substantiation of alleged abuse ('*no evidence of neglect*'). Concerns were closed when Aidan's weight and other observations and his eating and drinking appeared to have improved, and individual designated professionals (often the GP) were able to have an apparently reasonable conversation with adult A. The triangulation of ongoing and cumulative safeguarding concerns did not lead to an effective multi-agency strategy.

7.5.11 Bringing the increasing concerns under the statutory safeguarding framework much earlier and in a consistent way would have brought about the formulation of a multi-agency strategy and protection plan.

7.5.12 It appears from records that there were assumptions of protective factors in this case. D4L staff shared they became less and less of a protective factor as Aidan was more often absent from the day centre.

7.5.13 It also appears that adult B could have been assumed as another protective factor. In the earlier years, adult B expressed his concern about the care of Aidan by adult A and the condition of the bungalow. Professionals tried to gain access and co-operation via adult B. It became apparent that there was conflict and miscommunication between the brothers.

7.5.14 It was clear from the reviewer's conversation with the brothers that they totally supported each other's views. D4L managers shared with me that adult B had '*a lot of respect*' for adult A. ASC practitioners also shared adult B's clear view that adult A was more than able to care for Aidan. Professionals' communication with adult B did not result in improvement of adult A's cooperation with services.

7.5.15 The GP could have been assumed as another protective factor. ASC's analysis stated that adult A '*appeared to always seek medical assistance*'. However, the GP's intervention was largely reactive to the reporting of adult A and therefore to his need for advice including the prescription of anti-biotics when Aidan became unwell.

7.5.16 These assumed protective factors for Aidan were no longer in place as the situation continued to decline. A robust protection plan for him was missing.

7.5.17 Practitioners were reminded at the learning workshop of the key criteria under the Care Act 2014 of determination by the partnership of undertaking a SAR.

'*… an adult with care and support needs has died and the SAB knows or suspects that the death resulted from abuse or neglect*'[33]

7.5.18 Some participants found it difficult to name the abuse / neglect in the case of Aidan. Their responses reflected more about what they considered as reasons for the gaps in their practice, e.g. shortage of resources, lack of information and management oversight, and less about the significant concerns they had identified in adult A's care of Aidan.

7.5.19 ASC representatives appeared to be reluctant and uncomfortable in naming the abuse / neglect involving familial relationships, at reflection meetings with the reviewer and at the learning workshop.

7.5.20 The reviewer reflected on the group dynamics and potential power imbalance within the professional audience at the learning workshop. It

[33] Sections 44(1)-(3), Care Act 2014

may have felt difficult for other partners to challenge the lead role of the local authority in safeguarding work.

7.5.21 'Professional deference' is a tendency of professionals within a group to 'defer to the opinion of a higher status professional who views the risk as less significant but who has limited contact with the person'. This may have happened in this case, resulting in an overall risk adverse approach.[34] (see 7.8.11.7)

7.5.22 The advocate shared that those practitioners who were more able to recognise and acknowledge the abuse / neglect in this case were those who knew Aidan well. This highlights again the importance of working together with other partners who had a longer history of working with the vulnerable adult and their family, namely D4L staff and some of Sirona therapists in this case. An independent advocate would have offered added value through their one-to-one work with Aidan.

7.5.23 One participant offered 'unintentional neglect' in response to this question. Practitioners were invited to reflect on the impact of neglect on Aidan, whether intentional or unintentional.

7.5.24 The statutory safeguarding process provides a formal framework for addressing carers issues in this complex case. '*Circumstances in which a carer (for example, a family member or friend) could be involved in a situation that may require a safeguarding response include – a carer may unintentionally or intentionally harm or neglect the adult they support on their own or with others.*'[35]

7.5.25 '*When risk increases in relation to carers unintentionally or intentionally harming or neglecting the adult they support, often the carers are themselves vulnerable… feeling emotionally and socially isolated… and have no personal or private space, or life outside the caring environment.*'[36]

7.5.26 'Neglect' is stated in the Care Act as a form of abuse. The statutory definition of domestic abuse introduced by the Domestic Abuse Act 2021 includes different types of relationships, including familial relationships.[37]

7.5.27 Safeguarding concerns relating to the complex dynamics between the cared for person and the carer do not discredit the importance of that close relationship to the cared for or the dedication of the carer, even when harm or neglect is unintentional.

[34] https://www.norfolksafeguardingadultsboard.info/assets/documents/NSAB-Professional-Curiosity-Aug-2022-Final-.pdf
[35] Para 14.45, *Care and Support Statutory Guidance* updated 18/02/2025
[36] https://www.local.gov.uk/parliament/briefings-and-responses/carers-and-safeguarding-briefing-people-who-work-carers
[37] https://www.gov.uk/government/publications/domestic-abuse-bill-2020-factsheets/statutory-definition-of-domestic-abuse-factsheet

7.5.28 Reflection and learning on applying the Safeguarding Adults framework and Making Safeguarding Personal

7.5.28.1 At the learning workshop, professionals were asked to consider how the six statutory principles of safeguarding could be translated to 'I statements' for Aidan. This exercise, with the support of the independent advocate representing Aidan's voice, provided an important insight to the gaps in practice of the application of Making Safeguarding Personal in this case.

7.5.28.2 The powerful reflection from this exercise is summarised below.

Empowerment – Aidan says, '*I want to have choice and be able to choose what happens for me*'.

Prevention – Aidan says, '*I want to be safe. I want to live without being hurt.*'

The advocate added her comment here that people often don't know what is happening is abusive and need that explaining to them.

Proportionality – Aidan says, '*I know the people involved and I like them.*' The reviewer added her comment here, '*I want you to take time and I don't want you to change everything at once.*'

Protection – Aidan says, '*I may not want a report made about abuse because I value connection with my brothers.*'

Partnership – Aidan says, '*I want to know and like and trust the professionals, not necessarily knowing everyone but knowing one or two professionals who will manage my safety.*'

Accountability – Aidan says, '*I don't need a personal relationship with everyone but I need people whom I like and trust.*'

The advocate commented that Aidan may have liked to relate to photos of the professionals.

7.5.28.3 The definition of adult safeguarding refers to '*people and organisations working together to <u>prevent</u> and <u>stop</u> both the <u>risks and experience</u> of abuse or neglect, while at the same time making sure that the adult's <u>wellbeing</u> is promoted including, where appropriate, having regard to their views, wishes, feelings and beliefs in deciding on any action*'.[38]

7.5.28.4 Effective safeguarding work comes from multi-agency working with a coordinated and planned approach. Partner agencies should have a clear understanding of each other's roles and responsibilities, and work together to develop applied knowledge of the necessary and proportionate use of legal powers

[38] Para 14.7, *Care and Support Statutory Guidance* updated 18/02/2025

in safeguarding adults, sharing risk assessment and sharing decision making.[39]

7.5.28.5 Multi-agency strategy and planning meetings should include legal advice as a core element of management of complex cases, and clear time frames for exhausting all less restrictive options before the last resort of Court proceedings. Consideration of legal options requires careful planning under partnership arrangements for assessing and managing risks, instead of crisis management.

7.5.28.6 This informs recommendation 7 and 8.

7.5.28.7 The SGSAB business manager shared that this reluctance of professionals to name the abuse / neglect in familial relationships, also occurs in the work of the Children's Partnership. The South Gloucestershire Children Board has a Child Neglect Toolkit for Practitioners. It may be helpful to consider wider cross-partnership dialogue and agreement on raising professional understanding of neglect and the application of this in practice with adults at risk.

7.5.28.8 This informs recommendation 7.

7.6 Safe Care at Home

7.6.1 It did not appear that professionals spent time to analyse critically and work together to get to the nub of the issue, what care at home was really like for Aidan, and the significant adverse impact of isolation on him as the cared for as well as on adult A as the carer.

7.6.2 It was shared at a reflection meeting that the hospital team held an unrealistic view of what the community team could do, and the community team held an unrealistic view of the power of the hospital team. It was acknowledged that discharge could only be blocked if it was believed that care at home was unsafe, and safe care at home could only be observed in the actual home environment.

7.6.3 Reflection and learning on safe care at home

7.6.3.1 The Safe Care at Home Review (June 2023), jointly led by the Home Office and Department of Health and Social Care (DHSC), is an important reminder that people with disabilities, may be '*particularly vulnerable to harm because of their dependence on others and the complexity of their care needs*'. '*They might rely on other people for physical, mental or financial support, and may face difficulties recognising or reporting harm.*'[40]

7.6.3.2 The review acknowledges the excellent care and support vulnerable adults receive at home from unpaid carers. The human stories in this

[39] http://londonadass.org.uk/wp-content/uploads/2015/02/Pan-London-Updated-August-2016.pdf

[40] https://www.gov.uk/government/publications/safe-care-at-home-review

review highlight the complexities of identifying and responding to harm that may happen behind closed doors.

7.6.3.3 It is crucial not to lose sight of the fundamental right of all vulnerable adults including, in particular, those who are unable to represent themselves, to be treated with dignity and respect, and to be protected from harm.

7.6.3.4 The Safe Care at Home Review concluded on key themed areas where improvements are required for government action. The recommendations should be taken up by local Safeguarding Adults Boards concerning leadership and accountability including learning from missed opportunities, reviewing local response to safe care at home including equipping staff to understand and navigate the complex legislative framework, and analysing local data and research.

7.6.3.5 This informs recommendation 7.

7.7 Inter-agency communication and partnership work – information sharing and escalation, and multi-agency partnership work including shared risk assessment, management of harm and shared decision making

7.7.1 The analysis of documentation and the learning conversations the reviewer had with individuals indicated different single-agency responses, without coordinated multi-agency working.

7.7.2 Practitioners reflected in the learning workshop about disjointed work between hospital social work and community social work. They shared their view about the added value of the inclusion of social workers in the Adult Learning Disability Health Team (ALDHT). ASC is not a routine part of the MDT discussion in Sirona.

7.7.3 Community nurses and dieticians sit outside of the core ALDHT in the Integrated Nursing Team (INT). Sirona recognised the need for improved internal communication, e.g. via multi-disciplinary team (MDT) discussion.

7.7.4 Information sharing was focused on the continuing requirement of D4L staff and community nurses to report to ASC safeguarding, without clear professional agreement on a robust protection plan and contingency plan.

7.7.5 Better information sharing and closer partnership working between all services, including the GP and D4L managers who held historical information about Aidan and his family, could have provided triangulation and collated evidence of concerns to inform the bigger picture of the deteriorating situation.

7.7.6 A robust risk assessment and clear risk management plan supported by a multi-agency strategy could have put into question that the least restrictive option was no longer proportionate to the escalating risks.

7.7.7 The first national SAR analysis highlighted that '*a rigid focus on assessment processes, thresholds and eligibility was seen as unhelpful where it stopped practitioners and agencies from taking a person-centred approach when assessing and seeking to meet needs and to mitigate risks*'.[41]

7.7.8 The national analysis also highlighted that the poor recognition of risk meant that '*sometimes practitioners were simply not worried enough to take action*'.[42] In this case, the reviewer is of the view that the declining situation should have made practitioners '*worried enough to take action*', at a much earlier stage, in the best interests of Aidan.

7.7.9 D4L managers and the Sirona dietician recognised the increasing risks of harm to Aidan and voiced their concerns. They raised questions and challenges in multi-agency meetings about closing safeguarding concerns, maintaining the status quo and not seeing any meaningful changes. This did not result in multi-agency escalation.

7.7.10 In the group reflection meeting, the Dietician highlighted a sense that their professional expertise and judgement and their challenge to ASC safeguarding was not given due consideration.

7.7.11 The second national SAR analysis again highlighted the most prominent practice shortcomings include risk assessment and management (82%).[43]

7.7.12 It is acknowledged by the reviewer of the significant challenges professionals had in working with adult A, as he continued to decline and refuse intervention and contact. However, when repeated offers and referrals did not bring about meaningful improvement and change, timely risk assessment could have informed a different protection plan, including a multi-agency strategy at a much earlier stage.

7.7.13 It is essential in the face of escalating concerns to bring everyone under a clear multi-agency strategy including communication of the whole picture and agreement of the lead agency.

7.7.14 Practitioners reflected it would have been helpful for multi-agency meetings to allow time first for professional discussion, before the brothers joined.

7.7.15 There would have been added value to managing the escalating concerns through closer joint working, with D4L professionals in particular, and the identification and agreement of clear outcomes and related roles and responsibilities.

[41] https://www.local.gov.uk/publications/analysis-safeguarding-adult-reviews-april-2017-march-2019

[42] https://www.local.gov.uk/publications/analysis-safeguarding-adult-reviews-april-2017-march-2019

[43] https://www.local.gov.uk/publications/second-national-analysis-safeguarding-adult-reviews-april-2019-march-2023-executive

7.7.16 In their reflection meeting and at the learning workshop, D4L managers shared their frustration about feeling that their safeguarding concerns were not listened to. '*We felt like a nuisance. Professionals gave us a wide berth.*' They highlighted their good working relationship with ALDHT staff.

7.7.17 D4L managers shared their record of email communication with ASC requesting for amendments to the minutes of a safeguarding strategy meeting in March 2024. The details of the specific safeguarding concerns D4L raised were omitted and factual inaccuracies were not corrected. It appears to the reviewer that ASC practitioners, who were leading the safeguarding work, were reluctant to record the strong voice of dissent in the minutes.

7.7.18 ASC practitioners reflected they could have done more, e.g. seeing Aidan at D4L and at the ward. They acknowledged there were organisational challenges at the time of shortage of staffing resources and heavy caseloads, making it difficult to review chronology of events and triangulation of information to inform safeguarding decisions.

7.7.19 It was acknowledged at the learning workshop that internal and cross-agency escalation processes were not well understood and used by partner agencies. There were missed opportunities for escalation of ongoing and cumulative concerns when agreed actions were not leading to improvement and change.

7.7.20 The Dietician of Sirona shared that she raised her increasing concerns with their team manager and the head of dietetics. Internal escalation was not further progressed to multi-agency escalation.

7.7.21 South Gloucestershire Safeguarding Adults Board's Resolution of Professional Difference (Escalation) Policy is aimed to '*provide a clear framework for the resolution of professional differences in order to ensure a timely resolution that ensures that the needs of the adult are met*'.

7.7.22 The voice of the adult at risk is key in this policy. '*At all times the voice of the person who is the subject of the safeguarding concern should be heard, and their views and wishes taken into account.*'

7.7.23 The policy provides clear guidance of the escalation process with a flowchart and time frames for different stages, the indicative structure relating to a variety of agencies and a form for recording and monitoring decisions.

7.7.24 '*Providing a formal but clear way for concerns to be expressed and taken seriously is one way in which we can demonstrate our respect for our partners and stakeholders. Challenge is a key part of effective and healthy inter-agency working cultures and partner organisations should therefore*

view and respond to challenges brought under these procedures in a positive manner.'[44]

7.7.25 Reflection and learning on inter-professional communication and multi-agency partnership work

7.7.25.1 Robust multi-agency risk assessment must include open discussion and agreement on the management of risks, fully exploring the adult's history, and the power relationships and family dynamics in a complex case.

7.7.25.2 Robust multi-agency risk assessment must also include contingency planning. All professionals across the partnership should be part of the discussion about what could go wrong and what contingencies are needed. If the adult at risk cannot tell professionals, the partnership should agree on how they measure the success of their protection plan, including clear time frames and who does what.

7.7.25.3 The gaps in communication and partnership work between ASC safeguarding and D4L indicates what appears to be a lack of parity of esteem between the statutory services and third sector organisations. The reviewer has been advised by the SAR panel members that this has been a recurring theme in other recent reviews.

7.7.25.4 '*The point at which the adult stopped receiving a care service was often seen with hindsight as a missed opportunity for further investigation or a fuller multi-agency response.*'[45]

7.7.25.5 There had been no basis, since at least the start of the Covid pandemic, for other professionals to continue to rely on undertaking assessments of Aidan at the day centre and D4L keeping eyes on him.

7.7.25.6 The research of the Institute of Public Care (IPC) highlights the important role care providers can play in safeguarding and in SAR learning. '*There may be situations where a care service needs to take more of a lead to push things forward. Care services being proactive and confident in seeking a safeguarding response is a key issue, particularly for smaller care providers. This is one reason why we suggest a wider discussion about how the statutory agencies and care providers work together around safeguarding.*'[46]

7.7.25.7 In complex cases, multi-agency information sharing, discussion and planning needs to happen at the important frontline

[44] South Gloucestershire Safeguarding Adults Board's Resolution of Professional Difference (Escalation) Policy, September 2023, due to be reviewed in September 2025

[45] https://ipc.brookes.ac.uk/publications/how-can-care-providers-learn-from-safeguarding-adult-reviews/

[46] https://ipc.brookes.ac.uk/publications/how-can-care-providers-learn-from-safeguarding-adult-reviews/

level where practitioners work with the adult. Management of quality assurance needs to happen simultaneously at the strategic level where senior managers of the Partnership maintain strong leadership and robust oversight and ensure accountability. This may require independent chairing of meetings where a multi-agency strategy plan is coordinated, professional challenge can be raised and escalation triggered if required.

7.7.25.8 Learning needs to be supported by clear and robust single agency and multi-agency escalation pathways.

7.7.25.9 'A core feature of safer organisational and multi-agency systems is where there is a recognition of the value of challenge in order to avoid the risk of one view being formed of a case, thereby excluding other possibilities. A safer system is one where there is constant reflection and learning to inform quality enhancement, supporting a culture of professional challenge.'[47]

7.7.25.10 This informs recommendations 9 and 10.

7.8 Understanding and application of professional curiosity

7.8.1 Practitioners were invited to reflect at the learning workshop the barriers for them to applying professional curiosity in this case. They shared key words including time, limited resources, discharge pressures, long history, assumptions, risk of breaking communication and not knowing who was responsible.

7.8.2 Practitioners shared about their over-optimism about the provision of support to Aidan in the community and the oversight this was assumed to provide, and their continuing reliance on the reported updates on Aidan from adult A in the absence of other concrete evidence.

7.8.3 Hospital staff acknowledged that what they observed about the care of Aidan by his brothers in the clinical environment of the hospital could be very different from the daily reality at home, in complete isolation from anyone else.

7.8.4 GP records also show numerous telephone instead of face-to-face assessments of Aidan at home, relying on adult A to report symptoms over the phone rather than reviewing Aidan face to face. The ICB reflected that health care was reactive to medical emergencies rather than pro-active in improving and promoting Aidan's physical health, without consideration of the wider clinical or safeguarding context.

7.8.5 Research shows that 'normalisation' is another barrier to professional curiosity, where ideas and actions come to be seen over time as 'normal' for that person. Adult A was able to maintain and present the story he wanted professionals to hear; his privacy was respected and

[47] https://www.local.gov.uk/publications/analysis-safeguarding-adult-reviews-april-2017-march-2019

there was not enough challenge to him based on the clear recognition and assessment of potential risks.[48]

7.8.6 Carer stress can mask abuse/neglect, resulting in a lack of professional curiosity to observe and ask challenging questions. Aidan was an extremely vulnerable adult where he found himself in circumstances where other people exercised a lot of control over the important decisions of his life.

7.8.7 Respect for privacy, in working with the complex family dynamics of this case, stifled professional curiosity. It was difficult for those working in the frontline in health and social care to ask challenging questions, when they were spending a lot of time and attention on avoiding conflict and complaints.

7.8.8 It is acknowledged by the NBT Safeguarding Team that whilst a lot of work is being undertaken with encouraging staff to be professionally curious and to have courageous conversations, staff can be concerned about the risk of complaints being raised against them. This resulted in what appears to be a relative lack of attempts to engage with adult A and adult B whilst balancing the known risks for Aidan.

7.8.9 The reviewer observed from D4L managers' contribution to the review, that they were not afraid to ask Aidan's brothers and other professionals challenging questions.

7.8.10 It appears that the 'doing' a lot of the time was undertaken at a single agency level, leading to referral to another partner for a specific action and intended outcome. What was missing was a clear lead on decision making and coordinated joint working in an increasingly complex situation.

7.8.11 At the learning workshop, practitioners shared in an open way that they did have challenging conversations with adult A, but these did not bring about any change.

7.8.12 Reflection and learning on professional curiosity

7.8.12.1 The first national analysis of SARs (April 2017 – March 2019) highlights the need for practitioners to 'exercise sufficient professional curiosity' and 'authoritative doubt'.[49]

7.8.12.2 *'Autonomy was valued and promoted without attention to risk mitigation… Poor recognition meant that sometimes practitioners were simply not worried enough to take action.'*[50]

[48] https://www.norfolksafeguardingadultsboard.info/assets/documents/NSAB-Professional-Curiosity-Aug-2022-Final-.pdf

[49] https://www.local.gov.uk/sites/default/files/documents/National_SAR_Analysis_Final_Report_WEB.pdf

[50] https://www.local.gov.uk/publications/analysis-safeguarding-adult-reviews-april-2017-march-2019

7.8.12.3 The rule of optimism may result in professionals' uncritical efforts to see the best, concerns about consequences of intervention, minimising concerns, not seeing emerging patterns or not ensuring a consistent focus on the person at risk.[51]

7.8.12.4 Professional curiosity means questioning assumptions including over-optimism, addressing professional anxiety about working with individuals/families, being willing to have challenging conversations and holding respectful scepticism.[52]

7.8.12.5 '*Sometimes, professionals may place undue confidence in the capacity of families to care effectively and safely. This is coming to be known as 'the rule of optimism'*.[53]

7.8.12.6 This is '*a well-known dynamic in which professionals can tend to rationalise away new or escalating risks despite clear evidence to the contrary.*'[54]

7.8.12.7 Power imbalance appeared to have resulted in professional deference, and the dissent within the group was not carried through to managing professional differences and further appropriate challenge via escalation procedures.

7.8.12.8 'Safe certainty' is used to describe an approach which is focused on safety but takes into account changing information, different perspectives and acknowledges that certainty may not be achievable.[55]

7.8.12.9 Professional curiosity should be central to practice to support safeguarding both carers and the person they care for. Timely and careful assessments should be provided for both the carer and the person they are caring for[56], including understanding the competing needs of each and having separate focus on each.

7.8.12.10 Other barriers to professional curiosity include the lack of support and clear direction from supervision, complexity and pressure of work, which are directly linked to resourcing gaps across health and social care.

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[51] ADASS Advice Note, *Safeguarding Adults 2011*, ADASS Safeguarding Policy Network April 2011

[52] https://www.norfolksafeguardingadultsboard.info/assets/documents/NSAB-Professional-Curiosity-Aug-2022-Final-.pdf

[53] *Carers and Safeguarding Adults – working together to improve outcomes*, ADASS Advice Note April 2011 https://www.adass.org.uk/adassmedia/stories/Policy%20Networks/Carers/Carers%20and%20safeguarding%20document%20June%202011.pdf

[54] https://www.norfolksafeguardingadultsboard.info/assets/documents/NSAB-Professional-Curiosity-Aug-2022-Final-.pdf

[55] https://www.manchestersafeguardingpartnership.co.uk/resource/professional-curiosity-resources-practitioners/

[56] ttps://www.local.gov.uk/parliament/briefings-and-responses/carers-and-safeguarding-briefing-people-who-work-carers

7.8.12.11 If challenging questions and courageous conversations do not bring about meaningful change or reduce the potential risks of harm to the vulnerable adult, professionals need to ask '*so what*' and then '*so what*'.

7.8.12.12 This informs recommendation 11.

8. Other Related SAR Learning

8.1 This SAR highlights similar learning areas as the SAR of Brian published by the Keeping Bristol Safer Partnership[57]. The SGSAB business manager included learning from this SAR in their Stop Abuse Week activities of November 2024.

8.2 It is recognised that learning from reviews in the neighbouring areas included in the Keeping Bristol Safe Partnership – Somerset Safeguarding Adults Board, North Somerset Safeguarding Adults Board and Bath & North East Somerset Community Safety & Safeguarding Partnership, has not been shared in a systematic way to South Gloucestershire practitioners.

8.3 The reviewer is also aware of a previous SAR undertaken by the SGSAB, relating to family Z. Although this SAR was not published, the learning was shared in full with SAB members to ensure oversight by senior managers. Individual staff were given the opportunity to read the report with their manager and a learning session was delivered by the reviewer of this SAR to social workers.

8.4 The Practitioner Learning Brief on this SAR was published in November 2019.[58]

8.5 Panel members shared that individual agencies have their own processes for reviewing and promoting SAR learning. The reviewer believes that SAR learning can be made more effective if this is undertaken and delivered at a cross-partnership level, as it is important that learning is focused on how agencies could have worked better together.

8.6 This informs recommendation 12.

[57] https://bristolsafeguarding.org/adults/safeguarding-adult-reviews/brian

[58] https://sites.southglos.gov.uk/safeguarding/wp-content/uploads/sites/221/2015/05/SAR-Family-Z-Learning-Brief-Nov-2019.pdf

9. Positive Changes and Improvement Actions in Progress

9.1 Sirona care & health undertook an internal investigation and their End-of-Life team completed a Subject Judgement Review (SJR) on the care provided to Aidan, following his death. Learning has been identified including improving the quality of social care safeguarding referrals, improved documentation of safeguarding concerns, including telephone calls and emails within patient records, improved awareness and documented use of the resolution of professional differences process and improved communication and understanding of roles and responsibilities within Sirona.

9.2 Sirona's internal review also identified learning to support practice, including promotion of the use of internal MDT for complex cases to improve communication and understanding of other roles.

9.3 Locality leads of ALDHT are provided with regular supervision from the Sirona safeguarding team, who can also pursue escalation in cases of repeated safeguarding concerns and lack of progress. Safeguarding is part of regular discussion in MDT meetings; invitation is extended to external professionals. Working closely with social workers is recognised to be key.

9.4 Community nurses work on shifts and allocation is based on the level of experience and complex skills required of the case or the specific task. Continuity of care by community nursing has not been possible to date. Change is in progress including a move to bi-weekly allocation and further move towards zonal working, to enable named nurses to have more oversight over a smaller caseload.

9.5 The NBT Safeguarding Team is offering reflective safeguarding supervision to teams and is available to individuals or teams to talk through complex cases and difficult situations and decisions.

9.6 NBT is currently undertaking a Mortality Improvement Programme as part of a wider programme of work, improving the quality of SJRs by providing additional supporting information for reviewers to look at cases in a more holistic manner. The NBT Safeguarding Team is working with the Medical Examiner's Office to look at identifying safeguarding concerns at Post Mortem, including liaison, processes and referral mechanisms to the team.

9.7 The ICB Safeguarding team has developed a 'Was Not Brought guidance document', including visits arranged by an urgent care practitioner for missed appointments of adults at risk.

9.8 The NBT Safeguarding Team aims to highlight in training the Was Not Brought/Did Not Attend issue as a potential indicator of abuse or neglect, as this is recognised to be a wider issue in health and social care. The NBT teams approach the NBT Safeguarding Team for advice on this.

9.9 To improve the continuity of care in primary care, the GP practice is considering the development of micro teams (small teams of 3 to 4 practitioners) who hold responsibility for a set of patients.

9.10 The ICB team has planned training around professional curiosity and Oliver McGowan training which is mandatory for all staff.

9.11 The Designated Professional for Safeguarding Adults for the Bristol, North Somerset and South Gloucestershire (BNSSG) Integrated Care Board (ICB) is going to raise the issue of Learning Disability Mortality Reviews (LeDeR) vs SARs with the SGSAB to ensure that there is cohesion between the two processes.

9.12 D4L have since had an additional policy on escalating professional disputes built into their organisation's safeguarding policy.

10. Conclusions

10.1 This is a human story about one family, concerning a special bond between the cared for and the carer.

10.2 There are complex relationship dynamics between the cared for and his close family, as well as challenging working relationship dynamics between the family of the adult at risk and a range of social and health care professionals.

10.3 There is learning from this SAR relating to the fine balance professionals have to hold under the Human Rights Act between the right to private and family life, and the right of the adult at risk to life and to liberty and security.

10.4 '*Abuse is about the misuse of power and control that one person has over another. Where there is dependency, there is a possibility of abuse or neglect unless proportionate safeguards are put in place. Intent is not an issue at the point of deciding whether an act or failure to act on one or more occasions is abuse. It is the impact of what is done or not done on the person and the harm or risk of significant harm to that individual that arises, at the time or over time, which matters.*'[59]

10.5 It is important for professionals to uphold the right of the adult at risk to autonomy, and to promote their choice and control regardless of their significant disability and lack of mental capacity to make relevant care and treatment decisions. Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) establishes equal recognition before the law of persons with disabilities.[60]

[59] https://lx.iriss.org.uk/content/scie-report-39-protecting-adults-risk-london-multi-agency-policy-and-procedures-safeguard.html

[60] https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities

10.6 It is also important for professionals to find and record the voice of the adult at risk, to make sure that their wishes, views and beliefs are represented and their rights are secured.

10.7 Good safeguarding practice must incorporate Making Safeguarding Personal as well as the application of professional curiosity, to ensure professionals develop the confidence to have courageous conversations with the family whilst focusing on the wider wellbeing of the adult at risk.

10.8 Good safeguarding practice also requires applied knowledge of the interface between legislative framework covering mental capacity, safeguarding and human rights.

11. Recommendations

11.1 It is recommended for the SGSAB to seek assurance from relevant partners that robust measures are in place to secure the right of people with learning disabilities to have essential checks including annual health checks and health action plans, and important documents about their communication and wider wellbeing. Essential information such as communication passports should be shared and easily accessible to all health and social care professionals.

11.2 It is recommended for all relevant partners of the SGSAB to review and update their policies and procedures with regards to fulfilling their statutory responsibility of advocacy for adults at risk. All relevant staff need to understand the important role of rights-based, non-instructed advocacy. Clear information on referral processes, communication channels and available resources and networks is to be disseminated across the partnership.

11.3 It is recommended for all relevant partners of the SGSAB to review their policy and protocol with regards to their work with family (unpaid) carers, to ensure that their wellbeing needs and outcomes are integral to local services. All relevant staff need to understand the local offer for carers, including direct work and independent advice which can be provided by carers services.

11.4 It is recommended for the SGSAB to review the membership of the Board, to ensure that it includes meaningful representation and contribution of relevant local third sector partners, including advocacy and carers organisations.

11.5 It is recommended for relevant partners of the SGSAB to explore the potential of Family Group Conference (FGC) and other models of mediation in safeguarding work with adults and their families, and to consider awareness raising and training delivery.

11.6 It is recommended for the SGSAB to seek assurance from all partners that relevant frontline staff are trained and apply the statutory framework of best interests for adults who lack mental capacity for relevant decisions, including advance care planning, substitute decision-making authority, the role of independent advocacy and the overlap between the MCA and DoLS.

11.7 It is recommended for all partners of the SGSAB to review the application by relevant staff of Making Safeguarding Personal within the statutory safeguarding adults framework, to raise awareness of the wider definition of neglect and understanding of 'safe care at home'. Wider cross-partnership dialogue and agreement is to take place on improving professional understanding of neglect and the application of this in practice with adults at risk. This may include opportunities for multi-agency learning and reflection on neglect, such as training, toolkit and other resources.

11.8 It is recommended for the SGSAB to seek assurance from all partners that their staff are aware of their organisation's operational procedures relating to seeking legal advice, supported by senior management oversight. The partnership is to review the pathway for pursuing legal options at a multi-agency level.

11.9 It is recommended for the SGSAB to review the effectiveness of multi-agency risk management by aligning current multi-disciplinary team (MDT) pathways with the statutory safeguarding adults framework. The pathway must be compliant with the statutory S42 duty, supported by clear governance and accountability and strong leadership. Independent chairing of multi-agency meetings should be considered, to enable effective challenge between agencies, robustness of shared risk assessment and management and shared decision making, within an agreed time frame, and escalation to effect changes. A co-ordinated and collaborative response to complex safeguarding cases should be in place, ensuring improved connection and consultation across all relevant agencies including the GP and third sector organisations

11.10 It is recommended for all partners of the SGSAB to review and raise awareness of all frontline staff of their single-agency and multi-agency escalation pathways, including the South Gloucestershire Safeguarding Adults Board's Resolution of Professional Difference (Escalation) Policy. The SGSAB is to seek assurance on constructive professional challenge and resolution of professional differences, as part of a learning culture to be embedded across all agencies in the Partnership. This should include parity of esteem across all local partners including third sector organisations and provider services.

11.11 It is recommended for all partners of the SGSAB to review and ensure the application of professional curiosity by frontline staff, in complex safeguarding cases in particular involving relationship dynamics between the cared for and the carer. This should include the consistent support of frontline staff under internal supervisory arrangements as well as multi-

agency and inter-disciplinary reflection space. The learning should be facilitated at a partnership level, so as to promote discussion and dialogue across organisations.

11.12 It is recommended for the SGSAB to complete a systematic overview of SAR learning in alignment with previous SARs in their local area and neighbouring areas included in the Keeping Bristol Safe Partnership, with similar areas of learning and recommendations. Relevant partners should consider collating evidence from practice and local data, to plan delivery of in-depth SAR training which is focused on learning and case reflection from specific complex cases. The planning and delivery of SAR learning is to be undertaken at a cross-partnership level, to ensure the extended learning is focused on better communication and better partnership working.

12. Glossary

ALDHT	Adult Learning Disability Health Team
ASC	Adult Social Care, South Gloucestershire Council
BNSSG	Bristol, North Somerset and South Gloucestershire
CAF	Critical Analysis Form
CRPD	Convention on the Rights of Persons with Disabilities
D4L	Design 4 Life
DHSC	Department of Health and Social Care
DoLS	Deprivation of Liberty Safeguards
GP	General Practitioner
ICB	Integrated Care Board
INT	Integrated Nursing Team
IPC	Institute of Public Care
LE	Learning Event
LeDeR	Learning Disability Mortality Review / Learning from lives and deaths – people with a learning disability and autistic people
MCA	Mental Capacity Act (2005)
MDT	Multi-disciplinary team
NBT	North Bristol Trust
OGD	Oesophago Gastro Duodenoscopy
OT	Occupational Therapist
SALT	Speech and Language Therapist
SAR	Safeguarding Adults Review
SGSAB	South Gloucestershire Safeguarding Adults Board
Sirona	Sirona health & care
SJR	Subject Judgement Review
SWASFT	South Western Ambulance Service NHS Foundation Trust
ToR	Terms of Reference