



## **Themed Safeguarding Adults Review – Daniel and Ruth**

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## **1. Executive Summary**

### **1.1 Background and context for the review**

The Tameside Adults Safeguarding Partnership Board (TASPB) commissioned this Safeguarding Adults Review (SAR) early in 2024, following two unrelated SAR referrals in October 2023 which were made by different agencies. Both cases were screened by a multi-professional safeguarding panel on the same date in November 2023. Due to their marked similarities, it was concluded that a mandatory themed SAR should be completed to understand and review the circumstances of the families in both cases.

There are two significant factors that these separate care scenarios share, which is why they are being considered together. Both involved:

- a vulnerable adult with care and support needs who lacked capacity (under the Mental Capacity Act) and could not generally communicate their needs or experiences
- a sole family carer who was providing a very intensive level of care and support, typically across a 24-hour period on most days

Both families had been known to health and social care services over many years and there were concerns that organisations in Tameside could have worked better together to support both the adult with care and support needs and the family member providing care for them, often known as ‘carers’. Carers in this context are not employed or paid but are family members or friends who support an adult who could not manage without their help due to, for example, illness, disability, substance use, a mental health issue or a long-term condition.

The first case is that of a young man who very sadly died age 27. He is known as Daniel for the purposes of this review. Daniel had lived with cerebral palsy and developmental delay / a learning disability since babyhood. He could communicate with eye movement and answer yes/no questions by this method or by touching hands, but he wasn’t able to communicate verbally, which included whether he was in pain. As he got older Daniel suffered from scoliosis, or curvature of the spine, and he required 24-hour postural management which involves using specialist equipment and positioning techniques to help maintain good posture and protect usual body shape. Daniel required full-time care, including overnight, following a support plan which involved personal care, regular position changes, feeding which was via a ‘PEG’ tube into his stomach and management of relevant medication. His mother was his main carer but there was also regular support from a team of professionals including a specialist physiotherapist, an occupational therapist, the GP and District Nursing.

The second case involves an adult woman who is known as Ruth for the purposes of this SAR. Thankfully Ruth did not suffer lasting harm, however, significant concerns

for her safety arose following a conversation with her husband and carer at a hospital outpatient visit and as a result she was placed in 24-hour residential care where she remains. Ruth was 64 at the time of the safeguarding incident and had suffered from schizophrenia across her adulthood, however, very sadly she went on to develop early onset frontotemporal-like dementia. The presentation of Ruth's symptoms was very complex and included being doubly incontinent, alongside behavioural symptoms which involved persistent restlessness, she could not communicate verbally but was able to make sounds and gestures (which gave an indication of her emotions or needs) and she experienced a compulsion to put things in her mouth including chewing non-food items (hyperorality). Her husband was Ruth's sole carer and whilst he did request occasional respite care, and eventually a permanent 24-hour care placement for his wife, he largely provided all of the daily care and support for his wife whilst she lived at home. Ruth is of South-Asian descent and her first language is Urdu although she is also a fluent English speaker. There were no records of any specific care requirements for Ruth linked to her cultural needs or religious beliefs.

Because support for carers is recognised formally in law, alongside the adults they provide necessary care for, this review considers both perspectives and whether support needs were acknowledged and met for both the adults and the carers. The legal framework that sets out the approach to assessing and supporting adults with care and support needs, the Care Act 2014, also makes provision for the recognition, assessment of and support for carers. The formal vehicle for doing this is via a carers assessment.

Daniel's death was also the subject of a Coroner's Inquest where the conclusion was that he died from Acute Hepatic (liver) Failure due to paracetamol toxicity.

This report goes on to provide an account of the best understanding of the two care scenarios using a timeframe up to and including around a 2-year period before the incidents which led to each SAR referral in October 2023. However, because both adults and families were known to health and social care services for a significant part of their lives, relevant contextual and historical information has also been made available to the review and several professionals also talked about knowing and working with the family over several years.

Within the approximately 2-year timeline under review, which spans from around Summer/Autumn 2021 to Autumn 2023, the SAR has sought to understand the adults' and carers' contact with services in Tameside, including routine care and crisis care situations, what support was made available to the families, and professionals' and the family carers' perceptions of the situation.

The report uses information supplied by Tameside safeguarding partners based on their case records, their own organisational learning processes, and conversations or

reflective practice directly arising from Tameside colleagues' participation in the SAR process.

The findings of this SAR and recommendations are relevant to Adults' health and social care services (statutory and non-statutory), particularly where professionals are providing care and support to an adult with complex care needs who cannot easily communicate their needs or experiences themselves, as this inherently increases their vulnerability.

It will also be of interest to any professional or agency in any capacity that works with or meets carers who are providing care for an adult with complex and/or high support needs. The report highlights the need for professionals to consider *objectively and curiously*:

- the intensity of care being fulfilled by carers
- the complexity of family care scenarios including the possible motivations for and impact of refusal of external support
- the signs of escalating carer breakdown/stress
- how to proactively intervene if safe care cannot be sustained or becomes neglectful

## **1.2 The review process**

The review process followed for this SAR is adapted from the Social Care Institute for Excellence (SCIE) review guidance and quality markers, with a view to achieving breadth and depth in understanding what happened in both cases and highlighting safeguarding learning. The two cases were considered separately to ensure that each family care scenario was understood in its own right, but the learning from the process has largely been combined. Where a specific point relates only to Daniel or Ruth, this is made clear in the report.

The review was largely completed during approximately a 6-month period between March – August 2024 and consisted of the following elements:

- Provision and review of two case chronologies, from which the independent reviewer developed key lines of enquiry (KLOE) for discussion
- The formation of a multi-agency review panel to oversee and contribute to the review process
- Individual agency meetings and record checks to discuss the KLOE, with additional information provided by agencies as required. This included two internal learning review processes completed by Adult Social Care (ASC)
- Two practitioner meetings, where colleagues who had met and worked directly with both families were supported to discuss the case, plus one individual follow-up meeting. Multiple practitioners attended the Daniel

practitioner session, including the team of professionals had that consistently supported the family. Two managers of the teams who had supported Ruth took part in the practitioner discussions and one of these managers had known both Ruth and her husband over a period of years, being able to recollect them both before Ruth had developed dementia

- Production of an initial analysis report, discussed at the multi-professional Review Panel 2 meeting
- Production of a final analysis report including recommendations for comment by Review Panel 3

The findings, learning and recommendations set out in this report draw on these different forms of evidence, insight and collaborative discussion, to generate the best possible understanding of the circumstances of both families.

Involving family members and hearing their perspectives is a very important part of a safeguarding adult review. However, after careful consideration at the outset of the SAR, a decision was reached by the panel and the independent author that consultation with family members would not be appropriate due to there being ongoing parallel processes in relation to both cases.

A decision was taken therefore to proceed with the review process initially without family involvement. Because these two separate but similar incidents had emerged within a short space of time - both involving very vulnerable adults who lacked capacity - this gave an added sense of urgency to this SAR and Tameside safeguarding partners agreed that they needed to quickly understand what had happened in both cases and promptly act on the learning.

The parallel processes involving both families continued throughout the course of the review and were only concluded after the final report and recommendations had been drafted. However, in order to ensure that families still had a voice, a decision was made to pause the review at this stage to enable families to be approached.

Ruth's husband chose to contribute to the review via a direct conversation with the SAR author. Whilst Daniel's mum initially felt unable to speak to the SAR author, in a later meeting with a quality lead from one of the services, she shared her perceptions of the care and support her son Daniel had received, alongside support for her as his main carer. The father of Daniel also met with services to share his views. One of Daniel's adult siblings also contributed to the review by sharing their views over e-mail. These specific viewpoints have been incorporated into this report where relevant.

There are several observations that are worth initially summarising, as they apply to the experiences of both families.

- There was a sense from both families of them being 'alone with' the situation and having no choice about caring

- It was evident that both main carers did not generally experience the contact they had with services as helpful or responsive. Both referred to responses as slow, delayed, not forthcoming at all and on occasion inappropriate to the circumstances. They both referred to having to follow-up with services to find out what was happening. This was an obvious source of frustration for family members
- There was a shared view that the help that was suggested/available, especially the respite offer, was not regular enough for Ruth's husband and additionally in the case of Daniel's mum it was either difficult to access, could not meet Daniel's personal care needs, or the alternative care provided in the home could not be relied upon. There was a sense from both carers that care at home may have been more sustainable with the right respite support. However, as the review will go on to highlight, both Ruth and Daniel had relatively complex care and support needs, that also proved challenging for professionals to find solutions for
- Both main carers talked about the lack of a consistent lead professional/contact – for Ruth's husband this was a Community Psychiatric Nurse (CPN) and for Daniels mum it was a Social Worker
- Both Ruth's husband and Daniel's mum wanted to care for their loved-one at home, but Ruth's husband in particular felt that no care alternatives had been discussed with him or how sustainable caring for Ruth at home was likely to be into the future. He felt that more candid conversations could have been initiated by services before he reached a crisis point
- Both families felt that a key improvement for the future is better communication with and listening to the carer, including situations where the carer is reporting concerns about the health and wellbeing of the person they are caring for

What became clear to the author was the considerable difference between the practitioners' perceptions of their attempts to help or offer support and those of the families. Throughout the review process, especially in relation to Daniel's mum, there was a frequent perception across professions of a degree of resistance to additional support. However, family contributions suggest that this was because independently finding carers using a Direct Payment was too difficult for the family to manage and the alternative support that was available was not considered accessible or suitable, especially in the case of respite care.

### **1.3 An overview of the cases and care scenarios**

#### **Daniel and his Mum and main carer**

Very sadly Daniel died after a short stay in hospital in October 2023. The conclusion of the Coroner was that Daniel died from acute liver failure and paracetamol toxicity. Daniel was 27 years old at the time of his death.

Practitioners and family members said that Daniel was a lovely young man who liked slap-stick humour, listening to music, horror movies and he loved his pet cats. Daniel enjoyed interaction with people and it was felt that he benefitted from this, but as his scoliosis worsened it was noted that he became increasingly isolated due to being confined to his home and largely to bed. Family members said that Daniel also became particularly socially isolated from his friends and peers after he left college, following which he largely only had his Mum and younger brother for company. Practitioners said that whilst Daniel's medical needs were not unusually complex, his physical and postural needs were and this was an ongoing challenge to his quality of life.

In the three years prior to the period of time under consideration by this review, there was a history of safeguarding concerns. Between 2018 and 2020 records indicated that four separate safeguarding concerns were raised by professionals working with the family. They related to multiple concerns around Daniel's oral and personal hygiene, medication management, missed appointments with different professionals, a pressure sore, refusal of additional care and support and Daniel's mum's challenges with her own health and wellbeing issues. The fourth of these safeguarding concerns involved a home visit where Daniel's mum wasn't present and Daniel was found to be vomiting and was being looked after by his younger brother.

Across this time period, regular multi-professional meetings (MDT meetings) were held to support the family to respond to the safeguarding concerns and at one point an independent advocate was also involved. This process seemed to be concluded in March 2021 and notes made by the Learning Disability nurse state the clinical opinion that there were no outstanding issues relating to Daniel's healthcare needs however there were ongoing concerns around his social care needs and the ability of the family to meet those needs.

Daniel's mum participated in a carers assessment in August 2021 and based on the conversation, the overall assessment was that she was coping with the level of care Daniel needed and she again declined respite. She said however that she was unable to maintain friendships and personal relationships, comments which are suggestive of social isolation in her caring role and little time to pursue her own social and leisure interests. The response to this was to issue a carers wellbeing grant and signposting to further support for carers.

In the ensuing months, it would seem that there was an initial improvement in the issues professionals were concerned about, but in Summer 2022 District Nursing recorded multiple missed appointments and failed home visits to Daniel. In November 2022 Daniel's mum mentioned her concerns around Daniel's oral secretions and swallowing and although a referral had already been made to speech and language therapy, the physiotherapist followed this up and consulted with other colleagues. On a joint visit to discuss this further in mid-December 2022, the physiotherapist found Daniel to be acutely unwell and insisted that an ambulance

was called. It was reported that there was some initial verbal defensiveness and resistance to calling an ambulance by Daniel's mum

Initially in consultation with the physiotherapist, the hospital safeguarding team agreed to make a safeguarding referral to Adult Social Care and requested consideration of a full S42 enquiry to inform discharge planning and highlighting the need for an MDT meeting. After investigations by ASC and detailed discussions with Daniel's mum, the S42 referral was stood down to a safeguarding concern and Daniel was discharged home.

From the point of hospital discharge on 28 Dec 2022 to the end of May 2023 the notes provided to the review show that various health professionals (Occupational Therapy, Physiotherapy, District Nursing, Community Dietetics) all found problems contacting, speaking to or accessing Daniel to visit for routine appointments or those where new equipment, medication etc had been ordered. This was also the case when communication was via e-mail, which was Daniel's mum stated preferred method of communication.

Despite this, professionals were advocating on behalf of the family to try to address some of the challenges with the home environment and suitable equipment to meet Daniels's needs. The physiotherapist also raised a formal PALS complaint with the Greater Manchester spinal specialist hospital in relation to the follow-up of an ortho-spinal review for Daniel.

At the end of May, records show that consideration was given by the physiotherapy team to raising another safeguarding concern due to lack of access. Contact was made with ASC who spoke to Daniel's mum, who subsequently explained that she had been suffering from migraines. The same concerns were expressed by District Nursing at the end of June, but shortly after a second emergency admission was required for Daniel due to an infection with his PEG feeding tube.

Over the Summer, access concerns were documented by District Nursing and a surveyor who visited the family home also raised concerns about the condition of the home environment, which they felt had deteriorated significantly since previous visits. This triggered a referral into Adult Social Care and a social worker was allocated to the family and a home visit was completed in early August 2023.

Usual visiting and contact with the family by professionals continued during September 2023, including physiotherapy follow-ups around a spinal x-ray for Daniel and an attempted medication review by the GP. In early October it appears that a safeguarding concern was raised by Daniel's sister expressing concerns about his confinement to bed which was referred to ASC. The last home visit was made by District Nursing on 6 October to check for pressure sores and no concerns were raised at this time.

On 10 October an emergency ambulance was called in the early hours of the morning by Daniel's mum due to concerns about Daniel's breathing and appearance

which was not normal for him and he was vomiting. Daniel was admitted to hospital for treatment but very sadly he died on 19 October 2023.

### **Ruth and her husband and main carer**

Ruth has lived with schizophrenia during her adult life and was known to mental health services, as was her husband. The couple were described as adoring each other, being very close and they had always liked to do everything together, which included Ruth's husband organising a holiday abroad in Spring 2023 despite the challenges of Ruth's dementia. No other family were regularly involved in Ruth's care.

Ruth is estimated to have been living with early onset dementia for around 4 years prior to the incident which triggered this review. During this time Ruth's husband appears to have been a full-time carer to his wife. The background provided to the review suggests that Ruth's husband also had an active caring role for Ruth in relation to her schizophrenia.

The initial indications of Ruth's husband requiring respite or other social care-related assistance to support him in caring for his wife were in Summer 2018, but there was then a gap of 2 years before the family had contact with ASC again in the form of a joint Care Act Assessment. This came about due to a referral from the CMHT (the community mental health team) who were also supporting the couple. At this point Ruth's husband declined social care support believing that his wife's primary needs related to her mental health. Over the ensuing 9 months numerous attempts were made by the social worker and the CMHT worker to liaise around the couple's needs, but this was complicated by staffing changes and staff absence / availability. ASC closed the case in April 2021 but shortly after in June 2021 another referral was made by the CMHT.

The referral had been prompted by Ruth's husband feeling that he was not able to cope with the demands of caring without any respite support. The professional opinion of the referrer stated that Ruth now required around the clock care. It was also stated that Ruth was suffering with double incontinence and there were concerns around her personal care and a previous accident in which she had burnt herself. Following an assessment with ASC, concerted attempts were made to find a 24-hour care respite placement, both within and outside of the Tameside area, but there were no suitable vacancies and homecare 'sit and support' was offered as an alternative to enable Ruth's husband to attend an overnight social event, which seemed to work well.

Following this, Ruth's husband made another request for respite in Autumn 2021 but this was later cancelled due to a change of plans. There was again a gap in contact between Ruth's husband and ASC but the family's case remained open to ASC to facilitate his access to respite. Ruth's husband next requested short-break respite in May and again in August 2022 and later in August he requested a 2 week block of respite. Over the Summer Ruth's husband also expressed anger and frustration to

the community psychiatric nurse from the CMHT about Ruth's condition and what was causing it. (NB The diagnosis of early onset dementia had previously been described to Ruth's husband but he struggled to accept this explanation, feeling that Ruth had experienced a sudden deterioration linked to using a mental health medication). There are signs that Ruth's husband may have been experiencing carer stress and burnout based on his contact with services in Summer 2022 and his increasing requests for respite.

Ruth's husband request for a longer period of respite care could not be fulfilled immediately at the time of the request and he believed that Ruth had been placed on a waiting list for respite. ASC notes confirm that the request to be put on the waiting list of a particular setting had been made and it had been agreed that the provider would get back in touch once a place became available.

Home visits to the family by the CMHT continued over the intervening months and in February 2023 Ruth's husband recontacted ASC to chase up the respite request. At this point it became clear that Ruth's name was not on the respite care waiting list, which understandably caused upset and frustration for him.

Between March – July 2023 various visits by the CMHT were made to the family and Ruth's husband, expressed concerns about Ruth's nutrition and weight and various referrals were actioned. In Summer 2023 he also raised a formal complaint expressing concerns for his wife which was referred to the mental health professionals that were already supporting Ruth and him. Following a direct conversation between Ruth's husband and the psychiatrist, a hospital admission under the Mental Health Act was discussed for Ruth and this took place early in August for a period of just over 3 weeks.

Throughout Ruth's admission, there is documented evidence that Ruth's husband continues to feel that being at home is the best place for his wife and this view is expressed from early in the hospital admission, in ongoing discussions with doctors and through to the discharge conversation. A manager who participated in the discharge discussion recalled that Ruth's husband advocated strongly that discharging Ruth to his care at home was the best option for her and this was agreed with follow-up support from the CMHT. However, Ruth's husband also reported that he felt that he was given encouragement to continue to care for his wife at home.

Around 3 weeks after the hospital discharge, in the middle of September 2023, Ruth's husband contacted the CMHT to request that a permanent 24-hour care placement be found for his wife as he could no longer cope. He chased up this request twice during September and stated to one practitioner that he hated his wife and wished she was dead. This statement triggered a safeguarding concern and was interpreted as extreme carer distress and led to safety planning being discussed with him and what to do if he fell into crisis.

Early in October a routine CMHT visit to the family appeared to suggest a significant alteration in circumstances and Ruth's behavioural dementia symptoms had again

deteriorated. The request for permanent 24-hour care was escalated following this visit but it still proved very difficult to source suitable 24-hour support for Ruth.

On 13 October Ruth's husband disclosed in a routine outpatient appointment that he had tried to smother his wife with a pillow and was himself having suicidal thoughts. A safeguarding concern was raised which led to the Police arresting Ruth's husband and the ambulance service being called to take Ruth to hospital. The ambulance service reported Ruth to be in a highly agitated mood, initially showing distress through aggression towards the Police and ambulance crew, but later she voluntarily boarded the ambulance. The house was reported to be a state of extreme disarray with human faeces on the floor and little edible food in the property.

At the time of this review, Ruth resides in residential care.

#### **1.4 The key issues under consideration**

10 initial key lines of enquiry (KLOEs) were discussed with the safeguarding/agency leads most closely involved with and relevant to the case. A slightly adapted version of these questions was also explored at the multi-agency sessions with practitioners.

They were:

1. How are the Best Interests of vulnerable adults without mental capacity (under the Mental Capacity Act) reviewed, particularly if the level of care they require changes or intensifies and/or they are entirely dependent on one main carer for their care needs?
2. How was independent IMCA advocacy or other advocacy utilised in these situations e.g. extended family?
3. How is dignity in care and quality of life considered for such adults?
4. How were Carers Assessments and/or ongoing observations of the care scenario used to inform professional judgement? e.g. medication management including non-adherence to prescribed medication, neglect of the home environment/hoarding considered by professionals
5. How do professionals judge when care by a family member may be escalating into neglectful or unsafe care – whether this is *intentional* or *unintentional*?
6. Is contingency planning discussed with carers and families, including their ongoing capacity to provide care safely/cope with the demands of caring?
7. What avenues are open to professionals and practitioners to raise or escalate legitimate concerns about carer capacity to continue to care, including proactive use of the safeguarding system?
8. To what extent did the availability of suitable 24-hour care for the adults influence or affect care?

9. When the main carer appears to obstruct access to the adult with care and support needs, what is expected best practice?
10. Is there any learning from this case about how to constructively challenge a carer's refusal of support

There was also an open opportunity for colleagues to share other learning or good practice they felt should be highlighted as part of the SAR.

Following discussions with practitioners and services, these three themes with sub-themes were identified by the author as being central to the learning from both cases:

1. Safeguarding the needs and interests of vulnerable adults who lack capacity
  - a. Using the provisions under the Mental Capacity Act
  - b. Dignity in care and quality of life
2. Assessment, support and intervention for lone carers managing very intensive care scenarios
  - a. Carer assessment and contingency planning
3. Balancing the needs and best interests of the adult with the carer's wishes/views in complex care scenarios
  - a. Managing apparent refusal of support
  - b. Raising legitimate concerns around carer capacity to care
  - c. Thinking Family

## **1.5 Good practice learning**

The focus of a SAR is primarily to identify learning which will lead to practice development and improvements in the future, or which indicates a clear need to review process and procedure for example. The SAR has also identified examples of good practice and positive relationship-building with families.

The good practice identified in the review is collated here:

- In both care situations it was evident that some practitioners knew the care scenario and relational dynamics within each family, understood in detail the care needs of the adult and had also come to know the family carer well
- On assessment by ASC in August 2023, a detailed and person-centred account of Daniel was recorded and respite was discussed and offered, but declined by his mum.

- There were numerous instances of practitioners advocating for Daniel and his needs, especially in relation to adapting the home and identifying equipment that would have enabled him to spend more time outside of his bed and home environment, in order to give him a better quality of life
- Professionals in the community mental health team (CMHT) recognised the pressure Ruth's husband was under, as well as voicing this himself, and repeated referrals were made into ASC both as safeguarding concerns and as requests for carer breaks/respite care due to concerns around carer breakdown. However, whilst the referrals were proactive, the response to them by ASC was reported by Ruth's husband to be slow or conducted in an unhelpful way e.g. using an unannounced visit in response to a concern around potential carer breakdown
- Practitioners were also proactive in requesting assessments / making medical referrals e.g. in relation to the potential for spinal surgery to address Daniel's scoliosis. It was clear from the practice conversations that the physiotherapist and occupational therapist involved in his care had a clear-sighted view of the complexity of his physical / postural needs and saw this as a significant barrier to his quality of life. In Ruth's case, a referral was made to speech and language therapy at the request of the carer, who had hoped that it would assist with Ruth's communication abilities
- The specialist physiotherapist appropriately raised several formal safeguarding concerns around neglect and acts of omission, but these did not progress to full S42 safeguarding enquiries during the period of time covered by this review
- Despite the specialist physiotherapist being robust in her approach to safeguarding Daniel, she was able to maintain a productive and respectful working relationship with the main carer Daniel's mum. Feedback from Daniel's mum also suggests that she valued the input of the specialist physiotherapist and understood the intent to help and support her and Daniel
- In the case of Ruth, although Ruth's husband had been referred to ASC to explore respite opportunities on several occasions previously - in July 2020 and April 2021 and at that time had declined respite via ASC - on a third referral by CMHT the family's case was then held open by ASC for Ruth's husband to access assistance/respite more easily if his circumstances changed
- Professionals in both cases alluded to the occasional challenges of working with the main carer, due to inter-personal communication issues and factors associated with carer stress or poor wellbeing, but there was an evident acknowledgement of the importance of maintaining a good working relationship with the carer and professional continuity for the family

## **Detailed report**

### **2. Analysis by the key issues explored in the review**

#### **2.1 Safeguarding the needs and interests of vulnerable adults who lack capacity**

- a. Using the provisions under the Mental Capacity Act and the safeguarding framework

The legal framework provided by Mental Capacity Act (MCA) is intended to protect adults who lack the capacity to make decisions for themselves, such as who provides their care, who manages their finances and where they live etc. The MCA enables discussions to be initiated and decisions to be made about what is in the 'Best Interests' of a person who lacks mental capacity. Both Daniel and Ruth were protected by the provisions of the MCA.

The process of Best Interests decision-making has to be objective and based on evidence - it is described in the Mental Capacity Act Code of Practice<sup>i</sup>. Although the Act is intended to apply to anyone who works with or cares for an adult who cannot make their own decisions, including family or other carers, informal carers are not legally required to have regard to the Code of Practice.

In the case of Ruth, her husband was described as a fierce advocate of his wife's best interests and her care, who was willing to challenge and question professional decisions, including those around medication. At one point he stopped giving his wife a certain medication without consultation with the CMHT but when it was discussed with the psychiatrist a decision was made to withdraw the medication as it did not appear to offer any advantage in managing Ruth's condition. However, Ruth's husband reported that he had also been trying to have a conversation about the benefits and possible side-effects of this medication over several years and he felt there was no recognition that Ruth's symptoms could have been caused by her mental health medication, and no acknowledgement or discussion of this, although he had raised it multiple times.

All professionals who took part in the review consistently said that there were no concerns that Ruth's husband was neglectful or not providing an acceptable level of care for his wife, albeit under conditions that were recognised as extremely challenging. This meant that consideration of a Best Interests decision had never arisen, until Ruth's husband made two self-disclosures in September and October 2023 that he had had thoughts of harming Ruth and a suggestion that he had acted on this in October. Prior to this, the evidence provided to the review suggests that Ruth's husband behaviour was consistent with having care and concern for his wife's welfare and wellbeing, despite showing understandable frustration and sometimes anger at the huge impact dementia was having on her.

For example, he appropriately sought medical advice on Ruth's behalf by calling 999 and then visiting the hospital emergency department (ED) in July 2023 with concerns about an apparent allergic reaction affecting her mouth/face. He appeared to regularly attend medical and other appointments with his wife and showed active concern about her weight loss and nutritional needs in June 2023. He also

proactively sought support through respite when the level of care he was providing intensified and he eventually recognised himself (without professional prompting) that he could no longer continue to provide care for this wife. Based on accounts from services, although his contact with some professionals could sometimes be abrasive and strained, this was consistently attributed to carer stress.

Upon admission to hospital appropriate safeguarding and MCA measures appear to have been taken e.g. to secure a Deprivation of Liberty Safeguard (DoLS) and various forms of independent advocacy were also considered for Ruth in the context of multi-professional meetings.

In relation to Daniel, the practitioners meeting highlighted some differences in professionals' expectations around the response to safeguarding concerns and use of Best Interests decision making relating to Daniel. There are indications from the discussion at the practitioners event, and from the chronology supplied to the review, that ongoing, frequent safeguarding concerns should have been adequate justification for more thorough consideration of whether Daniel's care at home continued to be safe and in his best interests, initially by escalation to a 'Section 42' of the Care Act (S42) safeguarding enquiry.

Within the timeframe of this review, there was an evident opportunity to pursue such a S42 enquiry following Daniel's emergency hospital admission in December 2022, which was the direct request made to the ASC safeguarding team at the time. Although the decision to escalate a safeguarding concern to a full S42 enquiry is the legal responsibility of Adult Social Care, the direct request by the hospital for a S42 enquiry to be conducted was consistent with their level of concern and the discussions with the physiotherapist at the time of Daniel's hospital admission. There was a sense at the practitioners event that if a thorough S42 enquiry had been completed at this point - also taking into account the at least 6-year history of frequent, continuous safeguarding concerns and the apparent inability of the family to improve the overall care to Daniel - that this should have inevitably led to a consideration of Daniel's best interests. Practitioners who regularly worked with the family expressed some understandable frustration at the missed opportunity to independently review the family care scenario in the context of a S42 safeguarding enquiry following what had been a significant health event for Daniel.

The sibling who contributed to the review felt that Daniel's best interests were repeatedly misjudged or overlooked by professionals and the lack of independent advocacy for him contributed to this.

This highlights the importance of informed decision-making around safeguarding concerns and ASC acknowledged that safeguarding decision-making is continuing to undergo a number of improvements, dating back over the last 18 months, including:

- The use of clearer rationales for decision-making around safeguarding concerns
- Use of more retrospective information so that an individual safeguarding concern is seen in a wider context

- Authorisation of decision-making
- Safeguarding supervision

The practitioner event allowed colleagues from different teams and professional backgrounds to discuss their understanding and impression of Daniel's mum as Daniel's main carer. All practitioners said that they believed that mum had her son's best interests at heart but that her own mental health challenges, her physical health and the stresses and strains of essentially being a lone carer affected her ability to deliver what was a very intensive and demanding caring role. Members of Daniel's family also observed that Daniel's mum's disability status and how this impacted her ability to care were not properly taken into account by professionals when considering Daniel's care.

A notable variation that emerged through the discussion was the difference in perceptions of Daniel's mum by the team that regularly worked with the family and ASC colleagues, some of whom (ASC colleagues) it must be acknowledged had worked with the family for only a relatively short period of time. However, ASC staff tended to see Daniel's mum as a caring mum whilst the regular team around the family showed more professional curiosity and queried whether some of Daniel's mum's behaviour essentially constituted disguised compliance i.e. the appearance of a parent/carer 'complying' with agreed care plans and needs but not following up with meaningful action.

Practitioners said that small improvements had been made by ongoing professional involvement with the family in the past, partly through the use of MDTs, but that these positive changes were often only sustained in the short-term, which is consistent with disguised compliance.

However, the other feasible interpretation of Daniel's mum behaviour that the SAR must explore is that she was quite simply unable to sustain - as a largely lone, main carer - the significant 24-hour demands of caring for her son and his increasingly complex physical and postural needs. The contributions from Daniel's family also indicated that Daniel had needed 24-hour care from around the age of 11 and that not having appropriate levels of support or respite from that age onwards had placed a huge strain on the family. The review has concluded that it was not questioned enough by professionals whether it was reasonable or possible to expect any lone carer to provide the level of care Daniel needed, especially a carer with their own health challenges, in spite of the carer's own stated wish to provide that care.

Daniel's case poses questions around how repeated safeguarding concerns are understood and escalated in the context of a family care scenario that involves a very vulnerable adult who lacks capacity, and additionally, what level/type/frequency of safeguarding concern would be expected to trigger a Best Interests conversation. Although the Safeguarding and Mental Capacity frameworks are governed by separate pieces of legislation, Daniel's circumstances as described in this review highlight the opportunity to join-up thinking and practice around safeguarding and Best Interests decision-making should there be other adults in a similar situation in the future.

However, the key learning underlying all of the above issues is that open communication between professionals, and crucially the inclusion of all multi-disciplinary practitioner voices at key decision points e.g. Daniel's hospital discharge in December 2022, is essential to supporting families who are providing care to an adult with high-care needs who lacks capacity, in order to protect that adult from either intentional or unintentional harm. It would also appear that professionals didn't actively take into account the length of time that the family had been providing high levels of care for Daniel and the impact this had on them.

The conversation that took place at the practitioners' event as part of this review, where different professional perspectives and experiences of the family were shared, should clearly have happened in the context of a routine MDT meeting or specifically as part of the S42 enquiry request that was stood down by ASC in December 2022.

More generally, there is scope for reflection by the services involved in supporting both families about whether the level of proactive co-ordination and communication between them was proportionate to the needs of the families and the vulnerability of the adult.

#### b. Dignity in care and quality of life

In exploring with different services and professionals how dignity in care and quality of life are provided and maintained for adults with profound or complex needs, there were differing views. These included legitimate questions that some colleagues felt should be asked about whether expectations for adults with congenital or acquired cognitive or physical disabilities are generally too low and could lead to practitioners accepting standards of care for an adult with complex needs that would not usually be considered reasonable e.g. being largely bed-bound for 4 years, the independent voice of the adult not being heard, the adult having lost all social contact and friendships other than with his immediate family.

Learning Disability team professionals also shared experiences which they felt reflected a tendency for ASC social workers to prefer to discuss safeguarding issues in advance of the professional formally raising a safeguarding concern. It is not clear if the examples shared during the review process reflect prevailing practice in ASC or isolated cases by individual social workers. However, it requires immediate attention and reflection within ASC safeguarding, because practices which potentially seek to 'talk away' other professionals' legitimate concerns (or are *perceived* to seek to do so) are not defensible and can undermine trust and confidence between professionals, which could result in a reluctance to raise safeguarding concerns in the future.

Some practitioners also acknowledged that there is potentially a risk of poor levels of care becoming normalised by the same professional when working with families over numerous years, or equally, frequent changes of practitioner making it more difficult for incoming practitioners to challenge what may have previously been accepted. Regular multi-disciplinary discussion and constructive challenge is an important 'internal' safeguard to prevent poor standards of care becoming normalised.

Other colleagues felt that there had been continual attempts across professions to support Daniel's family and that Daniel's dignity and quality of life was an ongoing consideration. On balance, the evidence provided to the review supports this position, particularly the actions of the Learning Disability team who regularly supported Daniel and Daniel's mum, including Physiotherapy, Occupational Therapy and District Nursing. There are numerous examples of these professionals raising concerns and seeking to secure better standards of care and quality of life for Daniel, along with varied types of equipment and aids to make Daniel's mum caring role easier.

Social care-led reviews of Daniel's needs were undertaken annually in 2020, 2022 and there was a review planned for 2023, although the review in 2021 was missed. ASC felt that a wide range of options were discussed with Daniel's mum, including repeated offers of respite and the option of a personal budget. However, a family member questioned whether social care professionals had '*looked beneath the surface*' and felt that home visits should have immediately led to concerns around neglect.

It is not clear if it was attempted to incorporate Daniel's views into any of these social care assessments/reviews via an independent advocate outside of the family, or if this was seen as important or relevant. Some professionals observed during the practitioner discussion that it could be difficult to secure independent advocacy for adults in Tameside where there was a family member involved and advocates could sometimes end up advocating for the carer rather than for the adult.

In the case of Ruth, the main issues related to Ruth's appearance and incontinence and there were some open reflections by professionals about the absence of her voice in her care. However, these issues largely seemed to be in line with her dementia diagnosis and the care challenges associated with it. The only significant concerns about dignity in care arose in October 2023 at the point of Ruth's transportation to hospital, when it was noted by paramedics that both the family home and Ruth herself were in an extremely poor condition.

## **2.2 Assessment, support and intervention for lone carers managing very intensive care scenarios**

### **a. Carer assessment and contingency planning**

In both cases, carer assessments were offered to Daniel's mum and Ruth's husband. At the time, ASC colleagues acknowledged that contingency planning was not routinely discussed as part of the carers assessment conversation, but that this is something that could be introduced as standard to encourage an open discussion about what would happen in an emergency if the carer was suddenly unwell and also what long-term care options might look like. This is especially important where it is a lone carer providing the majority of the support their loved one requires. Contributors to the review observed that this more preventative and forward-thinking approach can help to avert carer crisis as well as unexpected hospital admissions for adults receiving largely family care. Adult Social Care

recognise this and there is work underway between relevant partners to routinely embed contingency planning conversations.

A possible barrier to practitioners initiating this conversation is that the type of residential care placement both Ruth and Daniel would have needed was not easy to source from the care market in Tameside. Daniel's physiotherapist and occupational therapist said that in their professional experience, his physical and postural needs were so specific that a bespoke placement would need to have been created for him. Whilst Ruth's age and complex dementia presentation would also have brought challenges in a market where the availability of dementia nursing care is reducing and is particularly challenging to source for adults living with young-onset dementia.

Ruth's husband did participate in both joint and carers assessments over a period of years dating back to 2014, the last individual carers assessment being in August 2021 and a comprehensive discussion with ASC also took place in August 2023. At all of these opportunities, it appears that either additional care options for Daniel were discussed or respite was explored as a means of giving Daniel's mum a break from caring, however, these were never taken up by her. The reasons for Daniel's mum declining support was typically documented as her feeling that she was 'able to manage', although there were signs to the contrary relating to Daniel's personal hygiene in one such assessment and a lack of curiosity about how Daniel's mum was getting enough rest herself when Daniel's care plan required 24-hour care. Cost was also a factor and a previous disagreement with a respite provider who had raised a safeguarding concern also seemed to be an influence in Daniel's mum refusal of respite care.

Ruth's husband chose not to participate in carers assessments although the chronology shows that multiple professionals mentioned them to him directly or asked for him to be referred for a carers assessment. ASC had a record of a carers assessment being offered and refused in February 2021. One professional's observation was that he always seemed to be a very resourceful man but was also a very focused thinker which made him more unlikely to participate in a discussion he didn't regard to be immediately relevant.

On contact with the family at a home visit in June 2023, the psychiatrist also suggested that a carers assessment referral be made. There is no documented reference to a carers assessment in the hospital discharge process in August 2023, however, in a home visit by the CMHT shortly after Ruth's discharge, possible packages of care were discussed with Ruth's husband who did not want to pursue these options as he felt they could be 'intrusive' and offer limited benefit to Ruth and possibly even cause confusion. He also provided assurances that he 'would reach out' if he needed more help or support with Ruth's care. In fact, he did this just a few days later.

In both situations, engaging the carer in discussions about support clearly proved challenging at times and credible reasons for the rejection of additional care or respite were offered by both carers to justify their decision-making. However, given the intensive and demanding level of care Ruth's husband and Daniel's mum were

each providing, there was scope for more professional curiosity, dialogue and creative persistence by some professionals.

In their contributions to the review, it was notable that whilst both main carers wanted to continue to provide care at home for their loved-one, neither one felt that other options for care were directly raised by professionals, although Daniel's family recalled that residential care had been briefly mentioned in the previous 12 months before Daniel's death by a temporary Occupational Therapist. Ruth's husband said that when his wife was discharged from hospital in August 2023 staff commented on 'how well' Daniel's mum was managing Ruth's care and he took this as reassurance, however, he also considered if this comment was intended to encourage him to continue caring for Ruth at home because there was no other suitable help available.

The complexities of forming a view on carer capacity to care and managing refusal of additional support by a family carer is explored in more detail in the next section.

### **2.3 Balancing the needs and best interests of the adult with the carer's wishes/views in complex care scenarios**

#### **a. Managing apparent refusal of support**

It has already been described that a feature of both care scenarios was a perceived refusal of regular mental health/social care provision and/or respite support by the main family carer, with services largely respecting the wishes of the carer, often without meaningful dialogue or challenge.

This did change in the case of Ruth and her husband, where occasional respite was requested by Ruth's husband from around Summer 2021, but professionals reported that his view remained firm up to August 2023 that having a care package, with carers supporting Ruth in their home, would not substantially help Ruth. It was said that Ruth's husband had commented that this was because Ruth needed help from moment to moment and could not wait for carers to arrive. His comment was suggestive that Ruth required 24-hour care, which the account of Ruth's 3-week stay in hospital seemed to corroborate.

In discussions with practitioners that knew the families, there are indications that Ruth's husband and Daniel's mum may both have felt a degree of mistrust towards professionals and services. Positively, this does not seem to have prevented professionals from forming a rapport with either carer, but there is a sense that the lack of trust on the part of Daniel's mum and Ruth's husband may have led to ruptures and strained working relationships with practitioners from time to time.

This underlying lack of trust seemed to be borne out of previous experiences with services and possibly also the carer's own individual beliefs system and mindset. Although no criticism was implied, professionals said that both family carers had a strongly-held belief that they knew what was right for their loved-ones. It was observed that Ruth's husband had also struggled to accept his wife's dementia diagnosis. It is very possible that these factors may have led them to be less open to

supportive suggestions from professionals and also more likely to take decisions without consulting them e.g. Ruth's husband withdrew Ruth's medication without prior discussion with the CMHT and Daniel's mum was reported as making spontaneous decisions to return new equipment designed to support Daniel if she didn't feel they were immediately helpful. It should be acknowledged that the carers' interpretations of some of these events was very different.

Several contributors to the review felt that these were influential factors in both carers' apparent resistance to receiving additional support or accepting what was offered, despite wider evidence suggesting that they would have benefitted from help. However, both main carers, Ruth's husband and Daniel's mum had a very different perspective, feeling that the support that was on offer was often not suitable, too inflexible or in the case of respite for Daniel, it could not be accessed without independent transport.

The learning from this review invites consideration of the complexity of family care scenarios and how professionals may interpret and work with what appears to be active or passive resistance from carers. There is no doubt that working productively with carers who have different views to professionals and who may choose not to follow the advice given, whilst also respecting their experiences and perceptions, and balancing that against the needs of the cared-for adult, is a professionally challenging dynamic which is explored in greater detail next.

#### b. Raising legitimate concerns around carer capacity to care and risk of neglect

There is understandably a dilemma for professionals if they see clear evidence that a carer is not coping and/or care isn't consistent or reliable e.g. signs of a very disordered home environment, medicines not being administered and/or stored in the right way, regular missed appointments or refusal of entry to the home, the care plan regularly not being followed, carer exhaustion or signs of distress, poor carer health etc, but the carer is not open to accepting support in the form it is available or offered.

The review explored what avenues are open to professionals to address a situation where their professional judgement is in opposition to that of the carer, because in effect it then requires them to challenge the carer's beliefs, experiences and viewpoints. This could be construed by the carer as doubts about their ability or commitment to caring for their loved one. It is therefore always a scenario to be handled with care, but the sensitivity of the circumstances should not lead to avoidance, inaction or allow failures in care to reach the stage of neglect or harm for the cared-for adult - *or* carer crisis and breakdown. There is some evidence that mental health practitioners working with Ruth's husband and Ruth raised safeguarding concerns as a vehicle to express 'supportive' concern about Ruth's husband ability to cope in his caring role. However, Ruth's husband reported that this did not lead to a productive response, with one unannounced visit by social workers causing him considerable stress and embarrassment.

When asked what avenues there are for raising this type of professional concern, managers generally agreed that the following approach would be taken:

- Initially discuss directly with the carer through use of professional curiosity and attention to the carer's wellbeing
- Raise with managers for discussion / at supervision and plan action
- Escalate internally and across partner agencies if no improvements seen e.g. considering use of MDTs to support change
- Use the legal framework provided by the safeguarding system to address the concerns about neglect/acts of omission (if the adult with care and support needs is perceived as experiencing neglect)
- Use the Best Interests process as judged appropriate – this could potentially be alongside the safeguarding process or following the outcome of it, especially if safeguarding processes do not lead to a satisfactory degree of improvement for the adult receiving care

One of the managers in the community learning disability team said that they also recognised that there had been scope for more formal managerial escalation to adult safeguarding based on the number of ongoing safeguarding concerns that had been raised by different members of the professional team around the family.

However, as well as having a process for practitioners to compassionately and confidently query the safety of family care if they have reasonable concerns, there must also be adequate training and support to enable all practitioners to recognise that family care situations cannot always be taken at face value, or on the word of the carer, especially when the cared-for adult has no independent voice. There are numerous occasions where there was an apparently superficial acceptance of Ruth's husband's account of events, particularly by ASC, which is also implied by one of Daniel's family members. This family member's opinion was that Daniel had experienced neglect, particularly in the final years of his life, but it had been overlooked by some professionals.

Good practice to avoid this in future could include active and objective consideration of:

- **the carer's motivations for wanting to be the exclusive provider of care to the adult** e.g. a sense of devotion and responsibility to the family member, a belief that only they can provide the care needed, embarrassment about letting other people into their home, a belief that the adult would not like or respond well to strangers, mistrust of others, the care and support on offer cannot meet the adults needs etc
- **whether the carer genuinely has the capacity or skills to provide the type and level of care required** e.g. reliably giving new or ongoing medication, managing distressed or dementia-related behaviour, using semi-clinical procedures, coping with frequent incontinence, use/absence of coping strategies
- **whether unintentional neglect could be occurring**, due to carer stress or their own health issues for example
- **whether there could be a pattern of disguised compliance by the carer.** Note that disguised compliance is usually associated with a hidden intent to deliberately harm, where the carer superficially agrees with professionals but

has no genuine commitment to change. However, it might also be motivated by a desire to reduce professional input in the short or longer term.

In the discussions with agencies and practitioners there was a sense that the emotional and physical capacity to care and 'skills for care' of both carers had been assumed, rather than objectively and candidly considered.

The review has highlighted that where a vulnerable adult who lacks capacity relies entirely on another individual to meet their basic needs, a robust and objective professional opinion should be formed and regularly reviewed, in consultation with carer, as to whether they are able to provide the care their loved one requires. This review is likely to be needed more frequently than an annual carers assessment in complex cases and particularly when a cared-for adult's needs change. For both Daniel and Ruth their conditions had grown progressively worse and although professionals had clearly recognised this, much less consideration was given to whether the carer was reasonably able to adjust to and cope with these changes in care needs. As mentioned earlier in this report, both main carers had also been providing care on a long-term basis which is important context for understanding carer resilience and ongoing capacity to care.

### c. Thinking Family

The concept of Think Family is very relevant when a family is providing most of the care and support for an adult and more so when only one carer is responsible for meeting most of their needs. The report has already discussed support for carers in some detail, but the second point is around wider family input and voice and how this could play a role in advocacy (for the adult and the carer) and decision-making.

In the chronology for Ruth and her husband there was no reference to any other family members. Daniel had a family, with several other siblings and a father that lived locally, but there is little evidence that these family members had any voice or influence in Daniel's care. However, in the week before Daniel's final admission to hospital, one of Daniel's siblings raised a safeguarding concern. There was also a belated recognition that Daniel's younger sibling who lived in the family home was acting as a young carer, perhaps sometimes having inappropriate levels of responsibility e.g. regular overnight care.

Several practitioners and agencies commented that it seemed like a missed opportunity to not have had a wider family perspective, because this could have informed professional judgements and added a wider voice and outlook on what must have been a very isolating experience for both main carers, Daniel and Ruth. The insights and contributions to this review by one of Daniel's siblings shows that other family members did have a view on Daniel's care, which could have informed professional judgement and decision-making.

## **3. Conclusions and recommendations**

### 3.1 Summarising commentary

This SAR has explored the circumstances of two families where an adult that lacked capacity was hospitalised in crisis. Very sadly, one of the adults Daniel passed away following hospitalisation and the other adult Ruth now lives permanently in residential care which supports adults living with dementia. In both situations, the crisis appears to have been precipitated by the gradual breakdown of family care, where a lone family carer had been providing an intensive and demanding level of care for their loved one over an extended period of years.

Both adults had progressive conditions e.g. they were likely to get worse but it could not be predicted how quickly this would happen. Daniel lived with scoliosis which had begun to severely limit his posture and positioning outside of a bed. However, some of the specialist team that regularly worked with Daniel felt that his scoliosis had advanced more than would typically be expected, complicated by a lack of specialist equipment that could respond effectively to his increasingly complex postural needs. In the case of Daniel, there was also a history of safeguarding concerns which centred around the capacity of Daniel's mother to provide the care that he required to enable him to live to his full capabilities, in particular, giving him regular opportunities to sit outside of his bed, leave his home and mix with other people.

Whilst Ruth had been living with dementia for several years, which affected her physically and behaviourally, it seems that during the period of time considered by this review her dementia symptoms grew considerably worse, to the point that an admission under the Mental Health Act was made in August 2023. In the months before this, her husband and carer had proactively sought respite on several occasions, and he eventually asked for a permanent residential care placement to be found for his wife because he could no longer cope. Unfortunately, due to reduced numbers of dementia care placements (especially one suitable for someone with early onset dementia), there were delays in finding permanent care for Ruth which seemed to precipitate extreme carer stress and care breakdown. However, professionals that worked with the family consistently agreed that there had been no concerns prior to this crisis that her husband was not providing appropriate care for Ruth.

The review has identified learning common to both family care situations. It explores the complexities of how professionals work with and support carers whose world-view and perceptions of what care and support is helpful and needed differ from those of professionals. This includes professionals actively seeking to understand why a family carer has apparently 'rejected' support when they are delivering a very demanding care role and the importance of maintaining professional objectivity and curiosity in relation to carers viewpoints and preferences, especially where the adult

with care and support needs lacks capacity and cannot verbally communicate their experiences or wishes for themselves.

There is a particular emphasis across the review on how effectively the legal frameworks that are designed to safeguard adults that lack capacity, protect adults from neglect or harm, and support carers were applied. The review has highlighted that multiple legitimate safeguarding concerns were raised by professionals in relation to Daniel, but the investigation of these concerns was often not robust or curious enough and lacked a historical perspective. It also includes making reasonable attempts to hear the voice of adults who lack capacity and routine check-ins / reviews for adults and families where external social care support or respite is limited or has been refused.

Lastly, a learning theme emerged around how professionals worked together, communicated with each other and co-ordinated support to the families and whether this was proportionate and responsive enough to these care scenarios, where the adult required a very intensive level of support. There were occasions when it appeared that not all practitioner voices were heard at key decision points and joint visits or multi-disciplinary conversations could have been used more proactively to inform professional perspectives on the family care scenarios. There is also learning around how professionals raise, discuss, escalate and respond to emerging concerns around carer capacity to cope and the risk of carer breakdown.

### **3.2 Recommendations**

The recommendations flow out of the evidence from the review process and aim to address the primary learning points relating to both cases. They are organised under the 3 primary themes of interest identified for this Safeguarding Adults Review.

#### **Safeguarding the needs and interests of vulnerable adults who lack capacity**

*Using the provisions under the Mental Capacity Act (MCA) and the safeguarding framework*

- a. Develop across the TASP, in collaboration with different professions and services, a shared understanding of and common partnership standards for working with adults who lack capacity (and their families and carers) which set out:
  - partnership/agency roles and responsibilities
  - the inter-relationship between the legal frameworks for safeguarding and the Mental Capacity Act/Best Interests processes
  - Expected information sharing standards and proportionate levels of communication, including use of multi-disciplinary discussions, in particular

where numerous disparate practitioners/services are involved in providing routine care for an adult who lacks capacity

- An agreed multi-professional process for discussing and escalating safeguarding concerns surrounding such adults, including but not limited to concerns around standards of family care or concerns about carer resistance to additional support
  - Approaches that avoid over-reliance on the family carers' perceptions or account of the care scenario
  - Use of Independent Mental Capacity Advocacy (IMCA) for the adult
- b. The TASP Board may also wish to consider:
- if the breadth of Mental Capacity Act (MCA) training is sufficient across the Partnership as a whole
  - if a more simplified version aimed at practitioners would be helpful to promote awareness of how to apply the MCA in real-world situations
- c. Although several agencies said that they already have clear policies around safeguarding supervision, the TASP Board should consider seeking assurance from Tameside health and social care agencies that reasonable levels of safeguarding supervision (managerial and/or clinical) are available to practitioners, in the interests of supporting staff and developing good safeguarding practice
- d. The TASP Board should work with Adult Social Care to support their ongoing investigations of how to appropriately increase the use of independent advocacy for adults at the point of a formal Section 42 safeguarding enquiry and/or Mental Capacity Act processes

#### *Dignity in care and quality of life*

- e. The TASP Board should reflect on and seek to improve local approaches that enable the voices of adults who lack capacity, and/or adults who do not communicate verbally, to be heard around their wellbeing and care preferences e.g. by offering support and guidance to Tameside practitioners around alternative communication tools and approaches, by more consistent use of independent MCA (IMCA) advocacy, through enhanced professional supervision
- f. In line with the actions already initiated by Adult Social Care, the TASP Board should seek assurance that routine management practices are in place to ensure that:
- adults with complex learning needs who do not have mental capacity receive a regular and timely annual review by Adult Social Care

- family carers of these adults who access limited external support to care are actively enabled by a learning disability specialist social worker to consider all alternatives to meet the care needs of their loved one
- family carers are also encouraged to take-up an annual carers assessment, which should include a discussion around contingency/future planning

## **Assessment, support and intervention for lone carers managing very intensive care scenarios**

### *Carers assessment and contingency planning*

- g. The TASP Board should seek assurance from ASC and local carer support services that contingency and forward planning becomes a routine part of a carers (re)assessment discussions and wider support conversations with carers, in particular where care is very demanding and/or long-term
- h. The TASP Board should explore and develop good practice for professionals on how to constructively but robustly:
  - start a contingency planning dialogue with carers who are delivering very intensive or demanding levels of care e.g. 24-hour care, complex or physically demanding care
  - work with carers who appear to be resistant to accepting additional support, where the evidence suggests that they are finding it difficult to cope with the demands of caring
  - reflect professionally on whether it remains feasible for a carer(s) to provide the level of care the adult requires
  - spot the signs of carer stress and breakdown, with or without suspected neglect
  - consider the potential for disguised compliance in family care scenarios

## **Balancing the needs and best interests of the adult with the carer's wishes/views in complex care scenarios**

### *Managing apparent refusal of support*

- i. The TASP Board should consider how to stimulate and improve professional curiosity and exploration of how cultural norms and/or faith and non-faith based beliefs systems influence care and support within family care scenarios, including refusal of support. This may be through enhanced learning opportunities or monitoring the response to diversity within health and social care scenarios

- j. Determine as a TASP how to strengthen decision-making and accountability at hospital discharge when a vulnerable adult with very high support needs is discharged to the care of a sole family carer. For example, by:
- actively noting and assessing the usual daily level of care the adult requires during the admission
  - using that insight to inform realistic post-discharge plans for care at home
  - candidly discussing professional/clinical opinion and concerns with the family carer

*Raising legitimate concerns around carer capacity to care and risk of neglect*

- k. In the interests of empowering front-line health and social care professionals, the TASP should seek assurance from Tameside partner agencies that they have internal measures and escalation processes in place to enable practitioner concerns around family care and/or neglect to be raised and appropriately addressed/escalated, *initially outside of* the safeguarding framework

*Thinking Family*

- l. The TASP Board should task partners with bringing relevant professionals together to reflect on how the learning from this review should inform local work around all-age and family caring. The round-table (or similar approach) should feed back the key points of the discussion and agreed actions to the TASP. The following points should be considered:
- improving the recognition of carer capacity/ability to care
  - support for isolated lone carers
  - the voice and role of extended families in complex care situations
  - the response to and voice of young carers, in collaboration with the Tameside Safeguarding Children Partnership

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<sup>i</sup> <https://assets.publishing.service.gov.uk/media/5f6cc6138fa8f541f6763295/Mental-capacity-act-code-of-practice.pdf>