Dudley Safeguarding People Partnership

SAFEGUARDING ADULT REVIEW

Report into the circumstances of Jed

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14/11/2024

Contents:

1 Introduction:

1.1 Confidentiality:

The following pseudonyms have been chosen to protect the identities of the people discussed within this Safeguarding Adult Review:

- JED - Review Subject
- JANETTE - Mother of Review Subject
- JOHN - Father of Review Subject

1.2 Background and Context for this Review:

On 7th October 2022, Dudley's Safeguarding People Partnership received a referral for a Safeguarding Adult Review from the Dudley Disability Service. The referral described the circumstances that led to a 33-year-old man, with severe learning disabilities and type III obesity (previously known as morbid obesity), being removed from his home due to serious concerns for his ongoing health and well-being. This gentleman will be referred to as Jed.

Jed has a severe learning disability which means that he needs help with all his activities of daily living. His parents cared for him until July 2022 when he was transferred to a care home. This transfer occurred because Jed's parents were unable to meet his care needs, and he required urgent intervention to address his deteriorating physical health. Jed was approximately 50 stones at this time. Jed was unable to independently leave his home due to his size and limited mobility. The local Hazardous Area Response Team was required to extricate Jed from the property via a window. A bariatric bed and specialised ambulance were needed to transport Jed to his new residence which was in an older adult care facility. The care provider made special adaptations to facilitate his access into the building and to provide personalised bariatric care.

On receipt of the referral, the Safeguarding People Partnership initiated a rapid review. The rapid review panel made a unanimous decision to proceed to a Safeguarding Adult Review (SAR) as mandated by section 44 of the Care Act (2014).

2.0 Review Process:

2.1 Rapid Review Decision Making Process:

On 17th April 2023, Dudley's Safeguarding People Partnership conducted a rapid review using a methodology similar to the one used for Child Safeguarding Practice Reviews[1]. The rapid review panel concluded that the case met the criteria for a Safeguarding Adult Review. The decision to proceed to a SAR was ratified by the Independent Chair of Dudley's Safeguarding People Partnership.

For the Rapid Review, organisations were asked to provide:

- A brief summary of the agency's involvement with Jed, focusing on key events in chronological order

[1] Child Safeguarding Practice Reviews are mandated under the Children Act (2004), section 16, subsection 1B, and are described in Working Together to Safeguard Children (2023)

- A brief analysis of agency practice including good practice examples and potential learning points.
- Information about any concerns the agency may have identified about the way partners worked together to safeguard Jed

The following learning points were identified by the rapid review panel:

- A whole family approach had not been used when concerns were raised
- There was a lack of formal safeguarding meetings held which could have supported Jed and his family
- Disguised compliance may have been present
- Obesity had not been seen as a form of neglect
- Pandemic restrictions (Covid 19 lockdown) had impacted upon Jed – he had become invisible to professionals
- There was an apparent lack of specialist placement for people with Learning Disability with bariatric needs

These points were taken forward to be included within the terms of reference for the SAR. The rapid review panel also stipulated that the SAR should consider:

- Hoarding and Self-neglect
- Escalation processes
- Risk Assessment
- The impact of carers' (parents) health on Jed's care and support.

2.1.2 Safeguarding Adult Review Methodology:

It was agreed that the SAR would be led by an independent lead reviewer and would use a multi-agency review panel to scrutinise information and formulate the report. The panel membership consisted of senior managers and designated professionals from the key statutory agencies, each of whom were independent of the case. The review panel used the chronological summaries provided to the rapid review and requested information reports from all involved agencies.

A focused approach was chosen with a remit to produce a report which:

- Reviewed and reflected upon the issues raised by the rapid review panel
- Reflected upon what professionals understood about the lived experience of Jed and his family
- Checked whether appropriate legal frameworks and statutory guidance was used when assessing and reviewing the care and support requirements of Jed and his family.
- Considered the context that agencies were working in and what barriers or challenges they faced when providing services to Jed and his family
- Identified good practice
- Provided learning points and/or recommendations.

A SAR panel was assembled comprising the following membership:

- Black Country Integrated Care Board
- Dudley Group Hospital NHS Foundation Trust
- Dudley Disability Service (Local Authority)
- Dudley Adult Social Care

- Black Country Healthcare NHS Foundation Trust
- West Midlands Police
- Dudley Community Safety Partnership
- West Midlands Ambulance Service
- West Midlands Fire Service

It was recognised by the SAR panel that family and friends can bring important insights and personal perspectives to reviews. However, the lead reviewer was advised that directly involving Jed and his family would be distressing for them. Therefore, the panel decided that their contributions would be obtained by proxy and an attempt has been made to incorporate their "voice" into the review whenever possible. Jed and his family were represented by his allocated social worker and the Deputy Manager of Jed's care home.

Information reports were provided by:

- West Midlands Police
- Dudley Group Hospital NHS Foundation Trust
- West Midlands Ambulance Service
- Dudley Disability Service (Local Authority)
- Black Country Integrated Care Board (Safeguarding Team and Continuing Health Care Team)
- Black Country Healthcare NHS Foundation Trust
- Dudley's Community Safety Partnership (Anti-social Behaviour and Housing Support Team).
- West Midlands Fire Service (verbal report)

The review focussed on the period between January 2018 – July 2022. The panel considered some information from outside of this timeframe for contextual purposes.

3 Pen Pictures:

The following section is included to illustrate Jed and his family, to depict some of the challenges they face and to offer an insight into their lived experience.

3.1 - Jed:

Jed has a diagnosis of severe learning disability, attention deficit hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD). He has type III obesity which is more commonly known as morbid obesity. He is described by professionals as being "non-verbal, having no concept of time or place and of being at a developmental stage similar to that of a 2-year-old child". This means that Jed does not have capacity to retain and understand information, make decisions for himself or have insight into his needs. He requires full support to enact all activities of daily living. For example, Jed is dependent on others to provide meals and drinks, and he requires some supervision when eating/drinking because he does it too rapidly and risks choking. He is doubly incontinent and has some issues with mobility due to his obesity. Jed uses body-language, such as head nodding, to make his wants known. His behaviour can sometimes be challenging, for example, he can scream and display self-injurious behaviour when he does not get his needs met in the manner he wants. He is dependent on others to act in his best interest.

Until 22nd July 2022, Jed was cared for by his parents in their family home. External support has always been required to help cater for his specific needs. This support was provided by social care

disability services and by mainstream and specialist health providers. The type and level of care provision was decided by care assessments (under section 9 of the Care Act, 2014).

Unfortunately, Jed's health and well-being was severely impacted upon because his care needs were not met. During home visits, professionals noted that he sat on a broken wooden sofa, which he was also using as his bed. He was dressed only in incontinence pads and underwear. He was thought to weigh approximately 50 stones with a Body Mass Index (BMI) of 87.5. This severely restricted his mobility. He did not leave the house and was not taken to arranged health appointments. He had red and swollen legs. His Mother washed him in their living room, using bottled water because she believed that their tap water was poisoned. She used incontinence pads to soak up the water and the carpet was saturated. Photographs taken by the ambulance service depict a very neglected home environment which was cluttered and in disarray. Professionals describe seeing a large collection of milkshake containers on the floor around where Jed sat. Jed is recorded as drinking approximately 12 "Yazoo" milkshakes per day which accounts for around 6,600 calories.

Jed has made huge progress, since he was moved into his current accommodation. He now weighs 24 stone, with a BMI of 42, which is half of what it was on admission. He is still morbidly obese, and his mobility is still limited. His carers say that his behaviour can be challenging when he is encouraged to walk because he enjoys staying in bed. However, he can now walk across his room and from bed to chair with a bit of help. His carers are currently trying to source a suitable wheelchair to enable outdoor activities. He has become fond of some of his carers, and he is very affectionate towards them. Jed can be contrary and when distressed he is prone to tantrums. He will cross his arms and legs and refuse to co-operate and occasionally he has been known to scratch staff when particularly agitated.

He likes peace and quiet, gentle music, watching cartoons and Teletubbies. He will attempt to do some colouring if he is in the mood and likes to play catch with a large blow-up ball.

His communication has improved since he moved into his Care Home. He is unable to use sign language or communication cards but can get his wishes understood. He can mumble and very recently has started to say No. He has an interactive tablet device which he loves, and he has started to use this to press picture related buttons indicating yes and no. Plans are progressing to evaluate whether Jed will be able to manage more independent living arrangements in the future.

3.2 Janette – Jed's Mother:

Until 2022, Janette, was Jed's main carer and acted as the "appropriate adult/person" for all aspects of Jed's health and well-being.

Professionals working with Jed knew little about Janette outside of her caring role. She is described as difficult to deal with, verbally aggressive, uncooperative and suspicious of professionals. She referred to herself a as full-time carer for both Jed and her husband John (although it is unclear why he needed care).

From 2019 onwards, concerns about her mental health were noted; she thought she was being poisoned by her neighbours. She was diagnosed with a Chronic Delusional Disorder[2] in 2020, following a Mental Health Act assessment. In 2021, she was recorded as having a Recurrent Delusional Disorder. She refuted having a mental health problem and has no insight into her delusions which seem persistent and fixed.

As well as not engaging with Jed's health and social care professionals, she was known to have difficult relationships with her neighbours. There were many police call outs about antisocial behaviour, and she was discussed at the Safer Estates forum[3] because of this. Most of the disputes with neighbours related to her delusions. A Community Protection Warning was served on Janette, via the Anti-social Behaviours team which she breached. Then an injunction was sought in May 2022.

Despite her delusions, Janette was judged to be mentally competent by professionals. She had a turbulent relationship with all professionals. Periodically, she would co-operate, and it seemed like she would accept support. She was occasionally open and would admit that she was struggling to care for Jed. She would then disengage or retract support when challenged. She has been described as particularly respectful of uniformed professionals.

Since taking over the care responsibility for Jed, the Deputy Manager of his care home has worked hard to befriend Janette. Initially she was difficult to engage with and was often hostile and abusive during conversations. However, with perseverance they have formed a relationship, and Jeanette seems to appreciate the interest taken in her. Unfortunately, Janette is now unwilling to work with other staff. For example, she will end telephone conversations rather than speak to other staff members if the Deputy Manager is unavailable.

Professionals who have worked with Jed have no doubt that Janette loves her son very much. However, it is evident that although her care for him was well intentioned, it was not always in his best interest. One professional referred to this as almost "killing him with kindness". She gave the following examples:

- Janette found it too difficult to challenge Jed's "difficult behaviours" and gave in to his desire for high calorie food and drink when he got upset
- Jed became highly anxious and agitated when he had dental treatment, so Janette chose not to take him to the dentist to avoid this. (He is now receiving dental care.)

It is possible that Janette was intimidated by Jed's presentation. He is reported to have occasionally lashed out when upset. He is very tall, approximately 6 feet 3 inches, and very large, due to his obesity. It may have been tiring and overwhelming to regularly face challenging behaviours, so she may have used pacification as a way of coping.

[2] Delusional Disorder (DSM5 – TR) – Definition: Presence of one or more delusions with a duration of 1 month or longer. The diagnosis of schizophrenia has not been made and apart from the impact of the delusions or its ramifications, the patient's function is not markedly impaired, and their behaviour is not obviously bizarre or odd. The condition has a chronic or insidious development of a permanent and unshakable delusional system.

[3] Safer Estates – now known as Safer Places – is a multi-agency forum which convenes every 8 weeks to discuss locations with a high frequency of callouts for services e.g. police, ambulance, fire, anti-social behaviour etc.

Since his move, Janette has not seen Jed. She talks to him on the phone/video call on a weekly basis and sends pictures and videos for him to view with his carers. She also sends him presents and cards and pays for clothes and haircuts.

The Deputy Manager told the lead reviewer that she believes that Janette has not visited Jed because she feels judged to be a bad mother and is ashamed and embarrassed. She has built-up a better understanding of Janette during their conversations. She describes Janette as an isolated woman who finds it difficult to cope with life. She believes that Janette tried hard to look after Jed and found it difficult to accept that she needed support.

The Deputy Manager does not see the situation leading to the breakdown of Jed's care at home as either disguised compliance or hoarding: rather she sees it as a broken family failing to cope. She also notes that Janette was probably self-neglecting and ignoring her own care needs. Since Jed has been looked after, Janette has been able to start caring for herself more and she has learnt how to use a "tablet" to help her communicate with Jed. The Deputy Manager suggested that it may now be a relief to Janette that Jed is being cared for in a way she is happy with. But that this is bittersweet because she was unable to achieve this level of care herself.

* The Care Home staff are working on finding ways to facilitate Janette to feel comfortable and safe enough to visit her son without fear of judgment.

3.3 John – Jed's Father:

Very little is known about John. He is 7 years older than Janette and is sometimes described as overweight, elderly and frail (he is 67 years old).

There are also some discrepancies about the state of John's health. Janette says that he has had a "nervous break-down" and suffers from chronic fatigue syndrome. She has told people that she is his carer. However, GP records do not confirm this diagnosis. In fact, neither parent seems to consult the GP very often. The couple seem to have a strong relationship. Information suggests that John always defers decision making to Janette. He seems to have colluded with her delusions and always backed her up during professional meetings.

The review could not find anything to describe what John's relationship with Jed was like. He has not visited Jed or made phone contact with him since he moved into the care home.

4 Overview of Significant Events:

This section provides a description of key events leading to Jed moving into his current accommodation following the breakdown of his care in the community.

4.1 Prior to 2018:

During his childhood, Jed attended a special school which catered for children and young people with profound learning difficulties. He transitioned into adult social care in 2008 and was provided with support from the Community Team for Learning Disability. Transition planning took a multi-agency approach which included input from the health care providers who were working with Jed at this time. He was provided with a package of day care from a specialist Day Centre with a 2:1 ratio of carers. The family were offered respite options which they declined.

Professionals noticed that food was being used by his family to manage his behaviour. Jed's parents were observed to be ambivalent about receiving support from agencies and an emerging pattern of initially agreeing to support, then disengaging, was documented. Jed's mother - Janette, is often referred to as being hostile or challenging towards professionals. Jed's father - John is rarely mentioned and little is known about his role as parent/carer.

As Jed transitioned into adulthood, concerns, which would later become chronic health and social issues, were already being noted by professionals. Jed's need for weight management was clearly documented.

The following are examples of emerging concerns:

- In 2015, he required a seat belt extension for him to be transported safely to the day centre.
- In 2016, Jed's parents asked for help to improve their bathroom, because Jed had some obsessional behaviours relating to hygiene, leading to environmental issues within the home. When offered bathroom modifications, Jed's parents refused to move out of the home for the building work to be completed. They also declined offers of respite.
- In 2018, concerns were raised to social care services by the Day Centre about Jed's weight increase, he was finding it difficult to walk, had red, ulcerated legs and needed bigger incontinence pads. He is recorded to be approximately 30 stones at this time.

4.2 During 2018:

In 2018, professionals had concerns about Jed's weight and a social care led multi-agency plan was formulated. On 05/11/18, after concerns were raised by his Day Centre, a Learning Disability Nurse and social worker visited Jed at the Centre and recorded his weight as 34 stones. A referral was subsequently made to the Promoting Access to Mainstream Health Service (PAMHS) so that weight monitoring and supportive health education could be provided to Jed and his family. A best interest meeting on 29/11/18, prompted a referral to the weight management consultant at the local general hospital. John was present at this meeting and the professionals agreed to give Jed's parents an opportunity to work with medical professionals on a weight loss programme. Unfortunately, despite this opportunity, his parents refused access to their home and Janette seemed reluctant to engage with professionals. She thought that he was eating a healthy diet and that his weight gain was down to a lack of exercise.

In addition to the concerns about Jed's weight, in May and October 2018, complaints were received by the Anti-Social Behaviour Team about Janette. The complaints were concerning behaviour associated with her delusions which were referred on to the Environmental Health Team.

4.3 During 2019

In early 2019, professionals recorded concerns about Jed's continuing weight gain and the lack of engagement they encountered from his family. Janette was sometimes referred to as being verbally aggressive.

On 5/3/19, West Midlands Police contacted Jed's social worker because they had been called out to disputes between Janette and her neighbour. Janette alleged that the neighbour was trying to poison her family. The police found no evidence to support Janette's claims, and they were concerned about the impact of these disputes on Jed's health. This episode was treated as a

safeguarding matter and a senior social worker was allocated to the case by the assistant team manager. Between 8/3/19 and 11/3/19, safeguarding concerns were raised in emails from a learning disability nurse to Jed's social worker and assistant team manager about Janette. She was concerned that Janette's response to information given about healthy eating and her belief she was being poisoned would affect Jed. At this time social care records state that Jed "has a severe learning disability and does not have capacity to understand and make decisions about his own life". The records also indicate that Jed's care provider (Day Centre) was struggling to meet his needs due to a change in his behaviour. A best interest meeting was held[4] on 8/4/19 at the family's GP Practice, but there is no formal documentation recording the outcome of this meeting. Efforts by the GP to visit Jed at home were blocked by Janette. However, the GP had a frank conversation with her about the consequences of not engaging with weight management on Jed's well-being and made a safeguarding referral. Janette was unhappy about this referral, so the family moved to a new GP Practice.

In May 2019, the Anti-social Behaviour Team became involved with the family following reports of screaming and shouting, and allegations of poisoning from Janette. Safeguarding checks were made which indicated that Janette was not known to Adult Social Care Services and a referral was made to Safer Estates and Dudley Tenancy Support Services. Janette was thought to have mental health issues and was directed to her GP for support. No link was made about the impact these issues may have had upon Jed by these teams.

During this time period, the review saw evidence that Jed's allocated social worker and all involved health agencies were attempting to put measures in place to improve Jed's health and well-being. But they were not working and by 29/08/19, Jed weighed 37 stones.

There seemed to be a lack of understanding about which agency was best place to lead on support for Jed as is illustrated by the following:

- 9/7/19, a phone conversation recorded on Jed's social care notes, documents that the District Nursing Service felt that their role was unclear.
- 19/7/19, Dudley's Clinical Commissioning Group (now Integrated Care Board) advised that before Continuing Care Funding assessment was considered that a social care led best interest meeting needed to be held
- 10/10/19, Dudley's Disability Service Assistant Manager documents that "Jed's issues are predominately health related, and professionals need to arrange a multi-disciplinary team meeting around risk management". (There is no documentary evidence to indicate that a meeting was held.)

On 30/9/19, Janette contacted Jed's social worker asking for financial support and food bank vouchers. This presented an ideal opportunity to conduct a full review of Jed's home circumstances However, this did not happen, and little changed with regard to his ongoing weight gain and other health concerns.

[4] A Best Interest Meeting is a multidisciplinary meeting that is arranged for a specific decision to be made about a patient's care / treatment, when a person is deemed to lack the mental capacity to make that decision for themselves. Best Interest check lists to be during assessments are covered in section 4 of the Mental Capacity Act (2005)

On 21/11/19, a Community Protection Warning was issued to Janette regarding her behaviour towards her neighbour. On 26/11/19, a referral was received by the Housing Support Team from the Anti-social Behaviours Team about Janette's verbal aggression towards her neighbour whom she believed was poisoning her. She was offered and declined two offers of housing support assessments. No concerns about Jed were identified, but Janette was given the phone number for the Carer's Network because she was known to be the main carer of her son. Opportunities to work with the family to support Jed were missed at this juncture.

4.4 During 2020:

On 06/2/20, a telephone call from the GP is recorded in Jed's social care case notes, asking for an update on the safeguarding referral they had made the previous year. The social worker advised the GP that the referral had not been progressed because the case was being monitored under case management. Other recordings in the case notes seem to indicate that the social worker believed that Jed's weight concerns were the purview of health providers, and it is unclear how inter-agency best interest decisions were being made.

On 27/2/20, Janette was referred for a Mental Health Act assessment by her GP. She was displaying symptoms of paranoia and believed that her family were being poisoned by neighbours. The Mental Health Crisis Team saw Janette at home and found that she was not detainable under the terms of the Mental Health Act. She was given a diagnosis of Chronic Delusional Disorder and was referred to the Home Treatment Team for further assessment. Janette declined to engage with the Home Treatment Team and was referred back to her GP. The Home Treatment Team asked her GP to make a safeguarding referral for the family and also one to the local authority for a carers assessment for John.

The following safeguarding concerns were communicated to the local authority:

- 13/2/20 - The police made a safeguarding referral relating to Janette's mental health and the impact this may have on her caring role for her son
- 5/3/20 – The GP made a similar safeguarding referral about concerns they had about Janette's mental health and its impact on Jed
- 9/3/20 – The Designated Adult Safeguarding Nurse escalated unresolved health concerns to the local authority's Safeguarding Manager about Jed and his family

As a result of the safeguarding referrals, an urgent multi-agency meeting was planned as per standard safeguarding procedure. The purpose of the meeting was to discuss Jed's best interests and to consider his removal from family care. This was scheduled for 20/3/20 but was cancelled due to emerging corona virus concerns. This was just prior to the national lockdown imposed on 23/3/20.

The safeguarding referrals noted above were viewed as "duplicates" from a referral made in 2019 and were subsequently closed.

Between 23/3/20 and the easing of lockdown restrictions in June 2020, there was no face-to-face contact with Jed by his social worker due to the local authority restrictions which stopped home visits. Jed did not attend his Day Centre because it was also closed due to pandemic restrictions. "Despite (local authority) protocols being implemented during the pandemic to safeguard vulnerable

adults; Jed's case notes do not indicate adherence to these measures by social workers or managers".[5]

No "joined up" risk assessment was conducted by the local authority or health providers to consider the unresolved safeguarding concerns, the lack of engagement with weight management support and the unsolved issues of accumulating bin waste in the house and garden. Intermittent complaints were received by the Anti-social Behaviour Team about screaming and shouting being heard at the property and about accusations being made by Janette about her neighbours attempting to poison her. They raised the reported concerns about anti-social behaviour at the safer places forum which was attended by mental health and social care professionals, yet this did not result in a partnership risk review or plan to intervene.

Information submitted to the review indicates that the GP discussed Jed in weekly meetings due to their concerns that he was not being seen by professionals. Specialist health services continued to try to gain access to Jed to monitor his weight, but this was generally blocked by Janette who was very concerned about Jed catching corona virus.

In October 2020, Jed's Day Centre re-opened and offered to provide support and social contact. This offer was declined by Janette. Jed's allocated social worker applied for Continuing Health Care funding. The social worker then left the organisation, closing Jed's case to active management and handing it over to the continuing health care social worker to handle the application. The application for funding was unsuccessful.

In November 2020, a safeguarding referral was made by the Anti-social Behaviour Team due to the nature of on-going complaints and concerns about Janette's behaviour. No mention of Jed was made within this referral, so it seems likely that no link between anti-social behaviour and its impact on Jed's well-being was considered.

4.5 During 2021:

On 13/1/21, a safeguarding referral was received from the Anti-social Behaviour Team who were concerned about Janette's behaviour and how it might be impacting on her son. Jed was appointed with a new social worker who repeatedly and unsuccessfully called the family. An unannounced home visit was conducted on 3/3/21 and a comprehensive discussion is documented to have taken place between the social worker and Jed's parents. Jed's weight and health issues, including his hygiene requirements, behaviours, need for socialisation and his mental capacity were covered within this conversation. The home environment was noted; the fireplace, vents and gaps in the doors were blocked up with blue incontinence sheets and there was an excessive build-up of black bin waste in the garden. Jed was observed to be dressed only in a pair of pants with an incontinence pad. Following this visit the social worker contacted the family's GP asking for more weight management and dietary support. The social worker also documented on 7/4/21, that an "urgent care act advocate was required" and that "although Jed's mother is the advocate for Jed, I do not believe that she is acting in his best interests". An urgent referral to an independent advocacy service was made.

[5] Taken from information provided to the SAR Panel by the Dudley Disability Service.

A mental capacity assessment was conducted by a new Assistant Team Manager on 3/3/21. This assessment went on to say that a best interest decision was to be completed and a risk assessment "to reduce the potential harm that may occur" was to be made. It is not evident from records if this happened.

On 6/4/21 another safeguarding referral was made following concerns being raised by a neighbour about Janette's ability to care for Jed; they overheard shouting. The social worker asked the family GP to refer Janette for a mental health assessment. The social worker and an Independent Advocate conducted a home visit on 12/5/21, and Jed's parents are said to have admitted that they were struggling and wanted some help. It was agreed that a care package including "morning calls" would be introduced to assist the family in managing Jed's needs, that Jed would re-start Day Centre attendance and that help with waste management would be provided. The social worker completed a risk assessment on 27/5/21, but the outcomes and multi-disciplinary approach to be taken was not recorded.

On 4/7/21 the Assistant Team Manager undertook another capacity assessment and recorded that Jed lacked capacity. The records state that Jed's care and support needs would be reviewed to see if he had sufficient care at home and risk management would be put in place, in his best interest. Unfortunately, there is no subsequent record that a best interest meeting occurred or if a risk plan was implemented – so it is not clear if this happened.

By September 2021, it would appear that agreed actions had not been accomplished and Jed was still not attending the Day Centre. The Promoting Access to Mainstream Health Services Team (PAMHS) contacted the allocated social worker to inform them that Janette was not bringing Jed to his weight management appointments and that they intended to discharge him from their service. On 15/10/21, the Probation Service contacted the allocated social worker to explain that Janette had been issued with an injunction to prevent her from contacting her neighbour. She had previously breached the terms of her Community Protection Warning. The Probation Service also contacted adult mental health services. They wanted to arrange a case conference because they were concerned about the impact of Janette's mental health and debts on her son. Jed's allocated social worker worked on a coordinated package of care for Jed and his family, but there was much left to do when this social worker left the service in December 2021. Jed's case management was left pending the reallocation of a social worker.

4.6 During 2022:

In February 2022, the Dudley Disability Service was contacted by Jed's Day Centre Manager who was concerned about Jed's increasing weight. A new senior social worker was allocated, who made a home visit to the family on 1/3/22. The social worker noted the deteriorating home situation and initiated urgent action to secure a support package. This package included the removal of accumulated rubbish, procurement of morning care, and referral to various health services to provide bariatric support including weight management and input regarding Jed's decreasing mobility. A multi-agency meeting was held on 27/4/22 to formulate a joined-up action plan. A second meeting was held on 10/5/22 and it was recognised that carer breakdown was imminent.

On 13/6/22, a safeguarding referral was submitted by West Midlands Ambulance Service who were concerned about Jed's health and well-being. Photographs were included to illustrate the state of

Jed's living conditions. They attended the home, because the social worker found Jed was unable to stand or get up from the settee. Jed's allocated social worker continued to work with the family who admitted that they understood that Jed needed to be supported into a place of safety where he would be able to access care for his deteriorating health. They recognised that he needed a period of rehabilitation to help him to lose weight and gain mobility. Urgent work was conducted to secure a bariatric placement. On 23/6/22, the social worker and an occupational therapist conducted a home visit and explored what specialist equipment could be sourced to help with Jed's immediate needs. The occupational therapist recorded that it was in Jed's best interest for him to be removed from his current circumstances. It was clear to all professionals that finding a care provider and extracting Jed from his home was going to be difficult due to his size and weight.

On 28/6/22 the social worker completed a capacity assessment; issue specific to Jed's decision making about his accommodation. On 30/6/22, a safeguarding/multi-disciplinary/best interest meeting was held to plan Jed's safe removal from his home into an identified care facility which had agreed to make urgent adaptations to cater for his needs. This course of action had been agreed to by Jed's parents and was deemed by all to be in his best interest.

On 20/7/22, Jed was successfully extracted from his family home by the Hazardous Area Response Team and was conveyed to his new placement.

5 Analysis - Recognising Concerns:

Throughout the timeframe covered by this review, practitioners from key agencies attempted to work with Jed and his family to support his health and social care needs. Despite this his physical health and general well-being deteriorated. Panel members from the rapid review raised questions about whether professionals understood or recognised the following concerns. The SAR panel undertook an analysis of these issues using the information reports provided by key agencies.

5.1 Hoarding:

A hoarding disorder is defined as when someone acquires an excessive number of items and stores them in a chaotic manner, usually resulting in unmanageable amounts of clutter[6]. The reasons for hoarding are not fully understood, but they are linked to individuals who have a practical inability to manage clutter, such as those with mobility problems, and to individuals with mental health conditions such as depression, or delusional and psychotic illnesses.

The panel received testimony from agencies working with Jed which described his home environment as being "unkempt", "in a state of disrepair" and "cluttered". It is clear that concerns about the state of the property were longstanding. All professionals recorded that the household conditions were unsatisfactory, with some describing this as hoarding and others as disorganisation and untidiness. The following are a selection of observations shared with the review:

- Bags and boxes of waste containing used incontinence pads were piled several deep within the living room and kitchen area.
- Used incontinence pads were on the floor and the carpets were wet and in a poor state due to Jed being washed with bottled water in the living room

[6] https://www.nhs.uk/mental-health/conditions/hoarding-disorder/#:~:text=A%20hoarding%20disorder%20is%20where,little%20or%20no%20monetary%20value

- Jed sat and slept on a broken settee and other seating within the home was also in poor condition with stuffing exposed (seen in photographs)
- There was a build-up of milkshake and other food containers on the floor and kitchen surfaces
- Incontinence products were used by Janette to plug gaps and vents to manage her delusions.

On 13.06.22, an ambulance crew who attended the property submitted a safeguarding referral with photographs attached to illustrate the disorder within the house. The panel have seen the photographs which depict neglected and unpleasant conditions which measure approximately level 4 on the clutter image rating scale[7]. This scale is promoted by Dudley Safeguarding People Partnership within their Hoarding Tool Kit[8].

The review was also informed that as well as being cluttered, that the property had been "insulated" by Janette who had taped incontinence padding to vents and around gaps in door and window frames. Professionals explained that this was in response to her delusional beliefs that she was being "poisoned" by her neighbour. She thought that a bleach-like substance was being poured through vents. Free airflow through the property was hindered by this "insulation" and some mould was noted. The review considered that it was likely that Janette's delusion led behaviour was at least partially causative to the poor condition of the property. She also admitted to some professionals that she was struggling to care for Jed. Information pre-dating the timeframe for this report also note concerns about the household environment, so it is possible that Janette found her caring role and keeping up with household tasks overwhelming.

With this in mind, the review found it difficult to deduce if the poor state of the family home was due to hoarding, chronic neglect or delusion-led behaviours; but thought it was likely to be due to a combination of all of these factors.

Despite actions being taken by social workers to help remove waste and provide support, the situation drifted and deteriorated. Improvement in conditions was unlikely to be sustained unless the situation was seen within the context of mental ill health. The SAR panel saw indications that Janette self-neglected and this was not recognised. Her delusions and propensity not to engage with professionals were identified. However, recognition of these behaviours did not result in action which actively named these features as causative to the environmental concerns.

Within the chaos of this home environment, professionals seemed to lose sight of Jed. Living in such conditions was not in his best interest and he did not have the capacity to care for himself, to influence the condition of his home or to choose where he lived.

5.1.1 Points to Consider:

[7] The Clutter Scale is a pictorial assessment/measurement tool, developed to give professionals a way to gauge the severity of clutter and hoarding. The rating was originally from a study by Frost RO, Steketee G, Tolin DF, Renaud S. Development and validation of the Clutter Image Rating. Journal of Psychopathology and Behavioural Assessment. 2008; 32:401–417

[8] The Hording Tool Kit was ratified in 2024 and is currently being promoted across the Safeguarding Partnership.

The review believes that the professional's involved in this case understood hoarding, but it is difficult to see how this understanding translated into action, particularly co-ordinated action across partners.

In order to improve services understanding of hoarding, in March 2024, Dudley's Safeguarding Peoples Partnership launched their "Think Family Hoarding Tool Kit"[9] with a corresponding training programme and with other excellent material on their website under their Neglect Strategy. Dudley's Integrated Care Board have rolled out the tool kit across primary care services and to all health providers. It remains to be seen if this will influence practice positively and the Safeguarding Partnership may wish to audit this in 12 months to measure how successful it has been.

5.2 Self Neglect and Neglect:

Self-neglect was identified by the rapid review panel as an issue which needed consideration within the SAR. The rationale for this was to determine if it was present and if so, if it was instrumental in the deterioration of Jed's health and well-being.

The definition of self-neglect is the lack of self-care to an extent that it threatens personal health and safety. It is neglecting to care for one's personal hygiene, health or surroundings. Furthermore, it is the failure to seek help or access services to meet health and social care needs.[10] .

The SAR panel agreed that Jed is not able to self-neglect because he lacks the capacity to self-care. However, Janette's presentation fits with the definition of self-neglect. Reviewing records to find out if Janette was self-neglecting falls outside of the information sharing agreements and remit of this review. But it seems likely, and her hostile attitude to professionals, refusal of offered support, lack of insight into her delusional disorder and role as carer may have stopped professionals from recognising that she had a problem in her own right that needed to be addressed. By proxy, self-neglect meant that Janette neglected to provide the appropriate level of care and support that Jed required.

The Care Act (2014) states that neglect (or acts of omission) occurs when a person deliberately withholds, or fails to provide, suitable and adequate care and support needed by another adult. This may be through a lack of knowledge or awareness, or through a decision not to act when they know the adult in their care needs help. This includes ignoring medical or physical care needs and failing to provide access to appropriate health and social care.

Jed was not given access to appropriate health and social care. Therefore, there is no doubt that he was neglected. The review took the view that instances of neglect constituted either carer and/or organisational neglect by acts of omission. The review believes that the neglect was the result of an insidious and inadvertent breakdown of care by his parents and was unintentional. Similarly, acts of omission and neglect by involved agencies were not deliberate or wilful.

Section 44 of the Mental Capacity Act (2005), says that social care services must "make consideration" of a person's capacity to make self-care decisions and should explore reasons around

[9] https://dudleysafeguarding.org.uk/blog/2024/03/21/dspp-think-family-hoarding-toolkit/

[10] Definition of Self-neglect and Neglect taken from the statutory guidance for the Care Act 2014.

service refusal, ill-treatment or neglect of a person lacking capacity. In Jed's case it is difficult to establish how such determinations were made and how his best interests were served.

- Jed was denied opportunities to access health and social care support.
- He had no capacity to control his dietary intake, and he became morbidly obese.
- Household management was beyond his capability and his living conditions were neglected to the point that his health was in jeopardy.
- Management of his personal hygiene was not appropriate and did not maintain his dignity.

The points above provide evidence of carer neglect and acts of omission.

Organisational neglect also occurred due to failure to act in Jed's best interest as outlined within the Care Act and Mental Capacity Act (section 4). Commendably, some organisations have reflected and now recognise that neglect was occurring, for example:

- Dudley's Disability Service have acknowledged "in hindsight and on reflection, that parental overfeeding and not engaging with health services to gain effective weight management was carer neglect". They also concede that "best interest decisions did not look at him holistically or at the possible impact on him of his parent's actions".
- Dudley Group NHS Foundation Trust admit to failing to recognise issues which they now consider constituted neglect or acts of omission.

Other services, such as the Ambulance Service and the Promoting Access to Mainstream Health Service (PAMHS), identified neglect and made safeguarding referrals about their concerns.

Having established that neglect was present, the Panel questioned why it was not reacted to in a successful way. The following explanations were given by contributing agencies:

- silo working by different agencies and departments
- restrictions to in-person contact imposed by pandemic lockdowns
- more risk management was needed regarding weight management and lack of engagement
- there was a lack of continuity of care caused by changes of social workers and line managers
- there was no formalised risk rating in place for cases of concern to guide priority allocation (of social workers) during the pandemic

It is clear that as well as the above factors, that family dynamics made it challenging for individual professionals to help Jed get the support he required. The review proposes that Janette became the focus of attention and that professionals were distracted from concentrating on Jed's needs, such as why he continued to gain weight and was not being presented for health appointments, and the poor conditions he was forced to live in.

A co-ordinated and planned multi-agency response was needed to act upon the concerns which constituted neglect. Oversight and coordination were lacking and there was no universal planning or goal setting put in place.

Whilst it was the responsibility of all agencies working with Jed to ensure that his best interests were promoted, the Disability Service were responsible for pulling everything together. Under the Care Act, the local authority carries statutory responsibility to organise safeguarding actions (under section 42) and to promote best interest decisions (as set out in the Mental Capacity Act). Unfortunately, the review found clear deficiencies in leadership by social workers and managers. There was also a lack of formal advocacy provision for Jed and incomplete documentation of best interest processes.

5.2.1 Learning into Practice:

Since Jed's move into formal care, Dudley's Disability Service has used their review of his case to improve case management and has put in place a traffic light (RAG) rating system to prioritise allocation of cases based on level of risk.

Dudley Group NHS Foundation Trust has implemented their learning by improving their training about self-neglect and extending their provision of safeguarding supervision.

Dudley's Safeguarding People Partnership conducted a thematic review of self-neglect (22/11/22) and produced and distributed seven-minute briefings about neglect and acts of omission. They also launched a new Adult Neglect Strategy (2024 - 2029). Priority 4 of the strategy is to "improve the effectiveness of interventions and reduce the impact of neglect on adults in the Dudley borough". This SAR would like to emphasise the importance of following through with this priority and notes that Dudley's Adult Safeguarding Board hold the responsibility to monitor the progress and success of the Neglect Strategy and have an action plan in place.

5.2.2 Points to Consider:

The Safeguarding People Partnership may wish to add to their current work on self-neglect and perform a deep dive into carer self-neglect outside of the SAR process. This would help to inform any future development of the "whole family" approach to safeguarding used in Dudley.

5.2.3 Recommendation One:

Dudley's Safeguarding Adult Board conduct 6-monthly reviews of the implementation of their Neglect Strategy Action Plan. The reviews should include all partner agencies and should measure compliance to the priorities and promote and share good practice examples to aid implementation.

5.3 Disguised Compliance:

Disguised compliance is a term favoured by child protection academics. It occurs when a family attempts to maintain the appearance of complying with plans to safeguard or promote the welfare of a child (or in this case an adult without capacity), but do not follow this through with meaningful action. Sometimes this may include a short period of improvement which is not sustained.[11]

Potential disguised compliance was identified during the rapid review process. Information provided to the SAR demonstrated that professionals working with Jed recognised a chronic pattern of poor engagement and resistance to change, but did not associate this with disguised compliance during the time period covered by this review.

Janette was described by professionals as resistant to offers of support and that she could be "difficult, obstructive, problematic and verbally aggressive". She would disengage by not taking their phone calls, refusing to allow them into the house, and by not taking Jed to arranged appointments. She did not seem to deliberately "disguise" whether or not she would engage or "comply". She simply failed to follow through with her obligations to provide appropriate care for Jed. This behaviour fits within the definition of disguised compliance and, as previously established, is neglect.

[11] Reder, P., Duncan, S. and Gray, M. (1993) Beyond blame: child abuse tragedies revisited. London: Routledge

With the benefit of hindsight the organisations working with Jed accepted that disguised compliance may have been present, but were still unsure that Janette's lack of commitment to planned interventions was intentional. The Dudley Group NHS Foundation Trust suggested that because disguised compliance is usually associated with child protection it was possible that workers did not associate it with adults as a safeguarding concern.

Viewing Janette's lack of engagement as a form of disguised compliance may not be helpful. Although her behaviour fits the definition, labelling it as such is simplistic. Janette seems to have been carrying the full responsibility of Jed's care within the family and she was struggling to cope. The impact of poor engagement and resistance to change should be broadened out to consider if professionals employed the "rule of optimism".[12] Previous safeguarding reviews have found that professionals tend to be overly optimistic and want to believe that "all is well". In child protection it is often described as professionals' inability to "think the unthinkable". Optimistic practice includes situations when the indicators of abuse/neglect are visible but are positively "explained away". Or the responsibility is seen as somebody else's, and the issues are left with the expectation that they will be picked up and fixed. This is not deliberate but has repeatedly been found as a factor which leads to failure to recognise and act upon neglect. The "seen but unseen"[13] victim of neglect has been the subject of numerous safeguarding reviews and remains a particularly stubborn practice problem to resolve.

The SAR panel suggest that turning the responsibility around from the review subjects to the involved organisations, is important when considering how to take single agency and partnership responsibility. It helps to ensure that innovative approaches are found to support and engage with people like Jed who are without the voice to challenge the status quo.

5.4 Obesity and Non-Engagement with Weight Management:

Class III obesity is a complex chronic disease in which a person has a body mass index (BMI) of 40 or higher. It is recognised that people with learning disabilities are at increased risk of being overweight or obese compared to the general population[14]. Those with limited executive function or who lack capacity, have little control of their dietary intake and often have low levels of physical activity. They require the support of others to remain healthy.

Jed does not have the capacity, or the level of executive function needed to make healthy dietary choices. He relied on his family and on professionals working in his best interest to make healthy choices for him.

Given that Jed had a BMI of 87.5 when the SAR referral was made, it is clear that his best interests had not been served whilst he was living in the community. Since moving into his current accommodation, Jed has lost 26 stones, and he now has a BMI of 42. He has been provided with a healthy diet and has been helped to engage in a weight management programme. This unequivocally illustrates that Jed's obesity is a result of neglect/acts of omission and a failure to act in his best interest.

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[12] This "rule", is a term used in child protection literature, and suggests that professionals tend to work from a premise of optimism and expect that parents love their children and do not normally seek to harm them
Dingwall, Eekelaar and Murray (1983)

[13] Cooper, Andrew. (2005) Child and Family Social Work – cited in; Surface and depth in the Victoria Climbie Inquiry Report.

[14] **https://www.gov.uk/government/publications/obesity-weight-management-and-people-with-learning-disabilities/obesity-and-weight-management-for-people-with-learning-disabilities-guidance#:~:text=Guidance,11%20September%202020**

5.4.1 Weight Management – Health Provision:

Information submitted to this review provides a catalogue of instances proving that Jed was not enabled to access weight management by his caregivers. Health providers pro-actively chased up missed appointments. Dudley Group NHS Foundation Trust's Weight Management Team and the Black Country Healthcare NHS Foundation Trust's Learning Disability and PAMHS Teams tried numerous reasonable adjustments in an attempt to get Jed weighed. Efforts to provide healthy eating advice to Janette were met with resistance. This lack of engagement was reported to social workers by health staff and was escalated to the Safeguarding Designated Nursing Team.

Efforts to help Jed to maintain a healthy weight were unsuccessful. The SAR panel were unable to establish how Jed's views, choices or feelings about his diet and weight were sought. They saw no evidence that issue specific capacity testing was conducted and recorded about his ability to engage with weight management interventions. Jed's views were represented by his parents who were considered to be his "appropriate adults". Jed did not benefit from having an independent advocate to represent him with regard to his engagement with weight management services.

There were missed opportunities to monitor Jed's weight via annual learning disability health checks. These checks should be provided by General Practitioners to anybody aged 14 or over who is on their learning disability register. Annual health checks provide an opportunity for a full review of an individual's health to be conducted, including weight management. The check-up should produce a personalised care plan which allocates actions to the individual and to professionals and carers. Jed's care plan could have provided motivational and practical support about diet and weight reduction strategies and clarified the role his parents and professionals played in implementing best interest decisions.

5.4.2 Responsibility to Provide Bariatric Care:

Professionals seem to have had some difficulty in understanding who held the responsibility to provide Jed with bariatric care and support and this led to some frustration. Some agencies stated that "silo" working was occurring and they felt that they were left with all the responsibility to find solutions. Different perceptions were held by the agencies about taking responsibility for leading on the funding of bariatric care, and agencies viewed their roles and responsibilities through very different lenses.

The following paragraph demonstrates how understanding about the parameters of care provision might differ:

- Local Authority View - Dudley's Disability Service made three unsuccessful applications for Continuing Health Care (CHC) funding. The applications imply that Jed's weight management and other health requirements were seen as outside of the social care jurisdiction and as "complex health needs" requiring an NHS funding solution.
- Health View - The NHS Continuing Health Care Team assess eligibility for CHC funding. CHC funding covers "complex care provision". This is health care which needs skilled and intensive (often invasive) high impact interventions. Jed's obesity and mobility issues require relatively low-impact interventions and do not fit the definition of complex care. Therefore, they would view funding as the responsibility of the local authority, via social care provisions with support from specialist NHS services.

Finding the right care for Jed was not easy. The SAR panel believe that agencies need some help to negotiate both the pathways, and the language used by individual agencies relating to bariatric care.

In 2022, Jed's circumstances changed following the appointment of an experienced social worker. She worked with local providers and obtained local authority funding for a care home placement (out of area). This provider was willing to work with the multi-disciplinary team to make rapid building adaptations to cater for Jed's bariatric needs. This demonstrates excellent practice by the social worker and the care home provider and was pivotal in bringing together all agencies to work effectively to deliver a cohesive health and social care plan.

Obtaining bariatric support for Jed was not straightforward and the following examples illustrate how agencies struggled:

- Jed's size and weight put him beyond the scope of most equipment parameters.
- Gaining out of area placement was complicated; the granting of funding and the issue of temporary residency led to delays.
- Sourcing equipment to aid recovery continues to be difficult and time consuming for professionals.

5.4.3 Learning into Practice:

The SAR panel acknowledges that GPs faced unprecedented challenges to their services during the pandemic. This impacted on their ability to provide annual disability health checks. The PAMHS are currently working with the Integrated Care Board and Primary Care Network on an audit of annual health checks as part of an improvement programme. They are also offering support and training for GPs and it may be useful to incorporate learning from this SAR into their training programme.

The National SAR Library holds many examples of how type III obesity and self-neglect are linked. This suggest that there needs to be more work done to strengthen how statutory agencies work together to effectively prevent obesity and to recognise and manage the impact when it is present.

In Jed's case, his dependency on others to help him access care was identified, but there was a lack of partnership agreement about how to manage this. There are ample legal frameworks in existence to use in such circumstances, but they were not properly implemented. Towards the end of Jed's journey into formal care, it was clear to the SAR panel, that professionals were confused about bariatric care pathways and who holds what responsibility.

5.4.4 Recommendation Two:

Dudley's Public Health Team should implement an "obesity work stream" which includes representatives from all key agencies. The work stream should report to Dudley's Safeguarding Peoples Partnership and will be responsible for:

- **Gaining an understanding of the work-forces knowledge about type III obesity**
- **Producing a seven-minute briefing about how to work with people with learning disability or a lack of capacity when weight management is required**
- **Promote knowledge about the link between neglect/self-neglect and obesity**
- **Produce a bariatric care guide for professionals which includes information about how to access provision and which clarifies roles, responsibilities and funding.**

6.0 Working in Partnership:

Practitioners from a wide range of agencies attempted to work together to support Jed and his family. However, the multi-agency response lacked co-ordination. At times agencies appeared to

operate as a discrete collection of services with diffused responsibility. The review panel were informed that “silo working was largely taking place” and that there was “no overall pulling together of agencies”. Most of the inter-agency communication and decision making took place between social care and health providers. The Police, Probation, the Anti-social Behaviours Team and Housing are not obviously included in safeguarding or best interest decision making, despite having contributed valuable information to both the local authority and to health providers. That said, the review stresses that all organisations do have a duty to proactively act on concerns and chase up referrals.

Fundamentally, a structured and formalised approach to address Jed’s needs was lacking. There was an absence of cohesive planning, inconsistent case management and a lack of strategic leadership and managerial oversight. This may have been due to frequent changes of staff within the Disability Service and the allocation of inexperienced social workers to a complicated case. There was no clear ownership of the case which led to “drift” and inactivity.

This changed when an experienced social worker took over Jed’s case management in April 2022. Thereafter, there was strong leadership and very good practice was evident from all agencies involved with Jed, leading to his safe transfer into a specialised care setting.

6.01 Multi-Agency Risk Assessment:

Risk assessment is the process used to reduce potential harm to individuals deemed to be “at risk of abuse and neglect”. When, the person in question lacks capacity, it becomes the responsibility of care providers to work in the person’s best interest to manage any risks on their behalf. Risk assessments for people without capacity should use either an “Appropriate Person” or an Independent Mental Capacity Advocate (IMCA) to represent their views.

The local authority under Care Act legislation held the responsibility to co-ordinate risk assessment and management for Jed via the Disability Team who were case managing his care package.

Risk assessments were performed by some of the agencies working with Jed or who came into contact with Janette. Concerns were raised to the local authority, either directly to Jed’s social worker or via safeguarding enquiries and referrals. These safeguarding referrals should have been used as an opportunity to initiate an investigation into how concerns about Janette’s mental health and anti-social behaviour impacted upon Jed’s health and well-being.

Regrettably, a complete risk assessment using a partnership approach to review all of the reported concerns about the family was not done until 2022. By this time Jed’s health and well-being were severely impacted and his care was in crisis.

Organisations were not drawn together to mitigate reported risks using section 42 safeguarding processes (Care Act 2014). On reflection the Disability Service agree that holistic assessment was lacking and state that “in the main no formal risk assessment or management processes were effectively employed during the build-up to the crisis”. The Disability Service acknowledge that “safeguarding’s (referrals) raised over several years, all resulted in case management approaches to try and resolve issues”. This approach did not result in effective safeguarding.

In summary, an analysis of risk factors and safeguarding concerns did not occur, and the quality of risk assessment and management fell short of acceptable and expected standards. Oversight and

leadership should have been provided by the local authority who held the statutory responsibility to do so under Care Act legislation.

6.1 Safeguarding Processes:

It is important to stress that the responsibility to safeguard adults with care and support needs who are at risk of abuse or neglect, belongs to everybody.

The review has already established that Care Act (s42) safeguarding processes did not bring together all partners as they should have. This seems to be because referrals were passed from MASH to the Disability Team to be followed up within case management. They then seem to have become subsumed into general case management rather than progressing to s42 enquiry involving other agencies.

Multiple referrals were received for similar concerns, but this did not elicit any analytical thinking about why the problems had not been successfully resolved. They were simply seen as "duplicates".

In short, there appears to be a problem with the safeguarding pathway. Referrals did not lead to active enquiry. Passing them to case management was ineffective and there were delays in response and sometimes gaps in allocation to social workers.

The SAR panel recognise that the Disability Team were working in difficult circumstances and that they experienced churn in their workforce. Changes of social worker, delay in allocation of social workers and changes of manager may have contributed to the gaps in safeguarding and best interest processes. The team was then affected by the Corona virus pandemic restrictions.

The review found concerning limitations to social work practice which appear to relate to system issues such as ineffective pathways and insufficient supervision of casework. The lead reviewer has been told by professionals working in Dudley, that safeguarding referrals triaged within MASH can remain unallocated for some time after being passed on to other teams. This is reportedly because there is a lack of case workers to pick up the referrals. It has also been reported that some of the social workers allocated to Jed's case were newly qualified or inexperienced and may have not had the ability to manage such a complicated case.

However, there was also evidence of excellent individual practice by social workers in Dudley's Disability Team, and this was ultimately responsible for Jed's recovery. Jed's current social worker recognised chronic neglect and reacted by instigating excellent partnership practice using s42 and Mental Capacity Act legislation. Thereafter, a clear process was followed, resulting in robust and effective safeguarding and best interest decision making involving all appropriate agencies.

6.1.1 Recommendation Three:

Dudley's Adult Social Care Service will provide Dudley's Safeguarding People Partnership with a two-part review of adult safeguarding practice:

Part 1 - review the safeguarding referral pathway from the point of concern for both allocated and unallocated cases.

- **Part 2 - audit the quality of s42 processes including making an enquiry, the involvement of other agencies and the documentation of all stages of the process.**

6.2 Escalation of Concerns:

Escalation is the process that professionals use to raise concerns about the safety of an individual or about the progression of a complicated case. During the timeframe covered by this report, Dudley's Safeguarding People Partnership were encouraging organisations to use the escalation process laid out in the West Midlands Adult Safeguarding: Multi-agency Policy & Procedures for the Protection of Adults with Care & Support Needs [15].

Between 2019 and 2022, concerns about drift in case management, the family's lack of engagement with health professionals, Janette's behaviours, and the home environment were escalated on numerous occasions. The escalations were made either directly to social workers, via safeguarding referrals or formally to heads of department. Unfortunately, they did not result in any sustained improvements and the Disability Service told the review that "it appears in case notes and later MDT discussions that supporting agencies did have concerns about the lack of engagement by parents and not having a robust escalation pathway for all stakeholders to follow resulted in inaction and silo working".

Internally, social workers escalated their concerns via supervision and to their line managers when they struggled to gain traction and engage Janette. Their review of Jed's case notes suggests that frequent changes of social care staff "seemed to hide the gravity of the situation", and that the pandemic impact on staffing effected the quality of managerial oversight and case management.

On the whole, this review found that professionals understood how to escalate concerns and established escalation processes were used. Unfortunately, this did not result in successful interventions being pulled together by the lead agency until clear leadership and co-ordination was put in place in 2022.

The review felt that the failure of escalations to improve Jed's circumstances is symptomatic of the lack of "grip" on his case as a whole. The Disability Service seem to affirm this in their statement that "resolution came, not through an identified escalation path but by effective Multi-disciplinary Team working bringing all parties together to share concerns and to problem solve within the safeguarding process raised by the allocated social worker".

The allocation of an experienced social worker was pivotal in making positive changes for Jed. Assertive and determined action was taken at speed by the social worker and partnership support was forthcoming and robust. This demonstrates good practice and the power of multi-agency working when delivered with direction and strong leadership. Nevertheless, an unambiguous process for escalation may have elicited a quicker response to concerns. Since this case was referred to Dudley Safeguarding People Partnership, they have put in place and launched a new Procedure for Multi-Agency Professional Challenge and Resolution.

6.2.1 Learning into Practice:

Dudley Group NHS Foundation Trust found during their review of Jed's care records that escalation processes were not used. They believe this is because the extent of poor engagement was not evident to them, and they did not recognise safeguarding concerns. As a result of this finding, they have put in place a standard operating procedure for people with Learning Disabilities who are not brought to appointments which was launched in July 2023 – this includes an escalation pathway.

[15] See page 84 -85 of the policy for details of the Concern Decision Making Tool.

6.2.1 Recommendation Four:

Dudley's Safeguarding People Partnership should seek assurance from all partners that their newly launched Multi-Agency Professional Challenge and Resolution Procedures is embedded into safeguarding practice.

6.3 Legal Literacy:

Legal frameworks and statutory government guidance provide structure to care interventions. The responsibility for applying social care law to practice is held by social workers, who need to be adept at navigating it, and at applying it to complex situations. The skills needed to apply legislation and interpret statutory guidance are often called "legal literacy". It is imperative that social care managers and social workers have a high level of legal literacy and create a team environment which promotes effective use of legal frameworks.

Throughout this report numerous opportunities to use legal frameworks which were missed or incompletely executed have been highlighted. Jed's care and support requirements should have been considered using The Care Act, the Mental Capacity Act and The Human Rights Act (1998). Guidance relating to the Corona Virus pandemic which should have been applied when assessing his vulnerabilities also appears not to have been used. The Disability Service acknowledge that "there are significant gaps in the recording of work undertaken and management oversight. It remains unclear why no Mental Capacity Assessments (MCAs) were conducted or documented during 2019, 2020, and 2021, especially given the escalating concerns about Jed's mother's mental health".

Because Jed lacked capacity and could not communicate his needs, he should have been given the opportunity to have his views represented by an independent advocate. As Janette and John's ability to act in Jed's best interest as "appropriate adults/persons"[16] was questionable, he should have had an advocate to help with Care Act reviews and for best interest decision making under the Mental Capacity Act.

Social care records seem to indicate that Jed has had an advocate since 7/4/21 to the present time. But this is inaccurate. The lead reviewer spoke with Jed's current advocate who explained that advocates are engaged per single issue because their service has limited capacity. For context, he currently has a caseload of 77 service users.

This advocate visited Jed at home on 27/7/21 to support a Care Act review. The advocate recalled that a plan was made by the social worker to get support for Janette to enable her to make some changes, aiming to reduce the impact of her problems on Jed. Jed was then discharged from the advocacy caseload as per normal practice – to be re-engaged for any further decision making as required.

In 2022, when Jed's circumstances became critical, an advocate was appointed to help make decisions to move Jed into formal care. Currently Jed has an advocate acting as his "Relevant Persons Representative" because he is subject to Deprivation of Liberty Safeguards.

This section of the report has concentrated on the local authority's legal responsibilities, because they were the lead agency in this regard. This does not mean that other agencies hold no responsibility for the gaps in the use of legislation. All statutory safeguarding partners are expected

[16] Appropriate Person/Appropriate Adult is terminology used within the Mental Capacity Act to define informal advocacy by an adult who knows the person without capacity well and is making decisions on their behalf.

to adhere to the relevant legislation applicable to the cases they are working, and this is generally written into organisational policy.

There is some information provided by health providers about their use of legal frameworks. For example, PAMHS used the MCA to help his GP to measure his capacity to use weighing equipment.

But there appears to have been a universal lack of legal literacy applied to Jed's circumstances and this needs further consideration to find its root cause.

6.3.1 Recommendation Five:

Dudley's Disability Service will conduct a review of their legal literacy using an audit tool such as the Safeguarding Adult Board Checklist for Care Act Statutory Duties and Policies[17] or the Research in Practice – Practice Tool[18]

The audit results will be reported back to Dudley's Adult Safeguarding Board with a clear plan to address any identified gaps.

The Partnership may wish to extend this recommendation to other involved agencies or specifically to safeguarding professionals.

7.0 Using a Whole Family Approach:

When assessing and planning care for an individual with care and support needs, it is widely agreed that it is beneficial to include their wider social network in the process; this is usually their family. Legal frameworks support this, and the Care Act states that "the intention of the whole family approach is for local authorities to take a holistic view of the person's needs and to identify how the adult's needs for care and support impact on family members or others in their support network".

It is evident that all agencies attempted to use a whole family approach when working with Jed and the review is satisfied that they understood the advantages of using this method of assessment and care planning. However, in practice they faced difficulties in delivering care interventions that truly met all the family member's needs. Janette's presentation frequently drew professional's attention away from Jed who should have been the focus of interventions. Jed's current advocate described how Jed seemed to be "diminished" by Janette. He explained that it was difficult for professionals to concentrate on Jed or to "hear his voice" because Janette's problems dominated the conversation. His needs became lost in his mother's narrative.

Janette's needs were not fully understood, assessed or addressed. Both she and her husband either declined or cancelled carers assessments and blocked attempts by the community of organisations working with Jed, to offer support. Janette's mental ill health went untreated and was described by one social worker as being "unresolved yet impacting". It is likely that she was self-neglecting to some degree. It is imperative that carer needs are considered when using assessment processes, but

[17] https://nationalnetwork.org.uk/Assurance%20Tools%20and%20Templates/Checklist%20Care%20Act%20Statutory%20duties%20for%20SABs%20Noc%202022%20(3).docx

[18] https://www.researchinpractice.org.uk/adults/publications/2020/december/working-with-people-who-self-neglect-practice-tool-updated-2016/

that this does not overshadow the needs of the dependent adult; they must be viewed as inter-dependencies.

The SAR panel saw evidence that proved that a well-executed partnership approach to whole family assessment and care planning using safeguarding parameters is possible. Thorough case management and leadership by the Disability Team in 2022 led to Jed's best interests being considered by both professionals and family members. Jed was successfully provided appropriate care outside of the family home with parental agreement. It seems likely that Janette is also benefitting from Jed's new care arrangements. She has now got more time to care for herself and seems relieved that her son's health and well-being has improved.

7.1 Learning into Practice:

Prior to their review of Janette's care records, the Black Country Healthcare NHS Foundation Trust had recognised the need to prompt staff to "Think Family"[19] during mental health assessments and have made improvements to both the triage and core mental health assessment documentation.

The Dudley Group NHS Foundation Trust are promoting professional curiosity with regard to "carer's mental health" and its impact on those being cared for.

8.0 Context, Barriers and Challenges:

During the time frame under review, Britain was subject to austerity policies which hit public services hard and impacted on staff morale. Services were stretched and struggled to provide anything other than basic services, which meant that complicated cases may have suffered from underinvestment. The cost-of-living crisis meant that many families were struggling financially. Jed's family seem to have been impacted in this way and are recorded as having debts and they were using the food bank at times. In 2020, society faced the extraordinary impact of the Corona Virus pandemic, and all public services were thrown into emergency measures.

8.1 Impact of the Pandemic on Jed:

The Corona Virus pandemic imposed three national lockdowns in England. The first was from 23/3/20, with various indoor and outdoor restrictions continuing until October. The second national lockdown came into force from 31/10/20 for four weeks. Then a third lockdown was put in place from 5/1/21 and various restrictions remained until 19/7/21 when legal limits on social contact were removed.

The pandemic and subsequent lockdowns created a new and unprecedented risk to people with learning disabilities. Everyone within public services worked hard to maintain continuity of care for their service users, but inevitably the situation caused a major reduction in service provision and a level of emotional distraction for staff. Staffing levels were impacted by sickness and staff taking time off for caring responsibilities. Over time, practice within the new working conditions became

[19] Think Family refers to guidance produced by the Social Care Institute of Excellence to prompt professionals to consider the impact of parental mental ill health on children – it is equally applicable to working with parents of adults with care and support needs.
https://staging.scie.org.uk/publications/ataglance/ataglance55.asp

more effective and services and staff adapted admirably, adopting new ways of working which has had a lasting impact on the way we work today.

Safeguarding and risk assessments were implemented by all public services to gauge who needed priority care. For Jed, these seemed to be ineffective.

The Disability Service made telephone contact with all their service users to perform a "safe and well check". For Jed, this does not appear to have taken into account his lack of capacity and the potential for "disguised compliance" by Janette. No other form of pandemic risk assessment was documented on Jed's social care records to evaluate his needs or whether prioritised case management was required.

The impact of the pandemic for Jed was considerable. His Day Centre shut down, which removed vital support from him and his family. His mother became extremely fearful for his health and restricted professional access to a minimum. In Dudley, the local authority did not initially have the technical capital to support virtual meetings and appointments. So, for Jed this meant that a crucial multi-agency best interest meeting was cancelled, and it was not re-scheduled. The Disability Service stopped conducting face-to face interventions and routine health provision both in the community and in hospital, reduced considerably, maintaining only essential contacts.

During this period weight management options were limited and access to Primary Care was in crisis. The PAMHS, Community Learning Disabilities Nursing Team and the GP recognised that Jed's lack of contact with health services was risky. They raised concerns to the Disability Team about his isolation. As restrictions reduced, Jed was offered some weight management options, but his family failed to engage. Jed's GP reviewed his case weekly in an attempt to keep an eye on growing concerns. The phlebotomy service provided by Dudley Group NHS Foundation Trust was the only health service to visit Jed regularly throughout the pandemic. They visited him at home to perform blood tests during the lockdown periods. But it appears that they worked in isolation and did not communicate with other teams working with Jed. This was a missed opportunity to gain valuable insight into his circumstances.

When restrictions eased, Jed's Day Centre re-opened offering a limited service. They offered Jed a chance to take some gentle exercise, but Janette declined this on his behalf.

During the pandemic Jed's weight increased hugely and his mobility declined to the point that he could barely stand.

In short, the pandemic isolated Jed from professional support and scrutiny. His health and general well-being rapidly declined.

The review found no evidence to indicate that comprehensive risk assessment measures were implemented during the pandemic to assess if Jed should have been prioritised for targeted intervention. There does not seem to have been a system-wide process put in place to counter these new challenges.

8.1.1 Points to Consider:

Dudley's Peoples Partnership may wish to determine if adequate safeguarding measures are now in place to provide system-wide risk assessment and management of "Never Events".

8.1.2 Learning into Practice:

The Dudley Group NHS Foundation Trust have put in place self-neglect training and bespoke safeguarding supervision relating to this case for the phlebotomy service. The phlebotomy team can also access ad hoc supervision in office hours. Dudley Group are also working on improving "informatics" to ensure that phlebotomy attendance is visible to other health care professionals on electronic systems/care records.

9.0 Summarising Commentary:

This review has considered the circumstances which led to Jed, a young adult with a profound learning disability, becoming so obese and immobile that he required a specialist team to remove him from his home. The SAR panel explored whether agencies could have done more, or acted differently, in order to protect him from harm and better meet his needs.

There is no doubt that practitioners from a wide range of agencies had concerns for Jed and were doing their best to engage with him and enable him to access support and healthcare. But a structured and formalised approach to collectively address Jed's needs and the risks that he faced was not put in place. This led to a dispersed responsibility and there was a need to ensure that case management and leadership was rooted in Jed's statutory rights to assessments, safeguarding and best interest decision making. The review noted a "whole family" approach was not taken by the agencies working with Jed.

This review focused on specific issues identified by the rapid review process and by the SAR panel. The review found that rather than there being a lack of knowledge or recognition of these issues, there was a failure to use a partnership approach to holistically consider the facts presented to professionals and to implement a joined-up plan for interventions. The lack of interagency corroboration of information and views meant that interconnections between specific issues, such as the link between neglect and obesity or mental ill health and hoarding, were missed.

The most important finding from this review is that Jed's voice was not heard. It was drowned out by other competing concerns and this review wishes to draw attention to the complex and nuanced decision making faced by those working with adults who are entirely dependent on others to protect their health and well-being. When considering mental capacity, safeguarding, and best interest decision making, clear leadership and legal literacy is imperative and needs more emphasis.

The review was greatly helped by the willingness of agencies to be reflective and non-defensive. Most organisations have put in place improvements following their review of Jed's circumstances, and some of these have been included within the report. Evidence was presented to the review which demonstrated organisational good practice. Excellent practice by specific individuals was also noted.

It is a collective responsibility to protect those without a voice in our society so rather than focusing on agency shortcomings, the following recommendations seek to promote partnership learning and resolutions.

10.0 Recommendations:

Recommendation One: Dudley's Safeguarding Adult Board conduct 6-monthly reviews of the implementation of their Neglect Strategy Action Plan. The reviews should include all partner agencies and should measure compliance to the priorities and promote and share good practice examples to aid implementation.

Recommendation Two: Dudley's Public Health Team should implement an "obesity work stream" which includes representatives from all key agencies. The work stream should report to Dudley's Safeguarding Peoples Partnership and will:

- Gain an understanding of the work-forces knowledge about type III obesity
- Produce guidance for professionals about how to effectively provide weight management for people with learning disabilities, poor executive function or who lack capacity
- Promote knowledge about the link between neglect/self-neglect and obesity
- Produce a bariatric care guide for professionals which includes information about how to access provision and which clarifies roles, responsibilities and funding.

Recommendation Three: Dudley's Adult Social Care Service will provide Dudley's Safeguarding Adults Board with a three-part review of adult safeguarding practice:

- Part 1 - review the referral pathway from the point of referral, through to the allocation of cases. This should include referrals into MASH and also the pathway for referrals which go directly to specific teams due to the safeguarding subject already having an open case file.
- Part 2 - audit the quality of s42 processes including making an enquiry, the involvement of other agencies and the documentation of all stages of the process.
- Part 3 – the Red-Amber-Green (RAG) rating system which has been introduced for the allocation of referrals to social workers should be audited to test its success at closing gaps in priority allocation of complex cases.

Recommendation Four: Dudley's Safeguarding People Partnership should seek assurance from all partners that their Multi-Agency Professional Challenge and Resolution Procedures is embedded into safeguarding practice.

Recommendation Five: Dudley's Disability Service will conduct a review of their legal literacy using an audit tool such as the Safeguarding Adult Board Checklist for Care Act Statutory Duties and Policies[20] or the Research in Practice – "Practice Tool"[21].

- The audit results will be reported back to Dudley's Adult Safeguarding Board with a clear plan to address any identified gaps.

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[20] https://nationalnetwork.org.uk/Assurance%20Tools%20and%20Templates/Checklist%20Care%20Act%20Statutory%20duties%20for%20SABs%20Noc%202022%20(3).docx

[21] https://www.researchinpractice.org.uk/adults/publications/2020/december/working-with-people-who-self-neglect-practice-tool-updated-2016/

- Dudley's Safeguarding People Partnership should extend this recommendation to other involved agencies and/or specifically to safeguarding professionals.

11.0 References:

11.1 Legislation and Government Guidance:

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11.2 Publications and Books:

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11.3 Hyperlinks:

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- https://www.gov.uk/government/publications/obesity-weight-management-and-people-with-learning-disabilities/obesity-and-weight-management-for-people-with-learning-disabilities-guidance#:~:text=Guidance,11%20September%202020
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- https://nationalnetwork.org.uk/Assurance%20Tools%20and%20Templates/Checklist%20Care%20Act%20Statutory%20duties%20for%20SABs%20Noc%202022%20(3).docx

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