



MK Together Partnership

Safeguarding Adults Review

'Adult D'

September 2020

Overview Report

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1. Foreword

1.1 This Safeguarding Adult Review was commissioned by the MK Together Partnership following the death of a vulnerable adult, who for the purposes of this report will be referred to as 'Adult D'. He was found deceased in August 2019. The MK Together Partnership incorporates local SAB responsibilities as set out in The Care Act 2014. The police advised that the date of his death was likely to have been around November/early December 2018. The cause of death will not be confirmed until the coroner formally decides at an inquest. For the purpose of the SAR, it has been treated as self-harm. A rapid review was completed in August 2019.

2. Introduction

2.1 Adult D had lived overseas and returned in 2009 to the UK to attend university. During his first term at university, he struggled to adjust to university life. In 2012 at the age of

21 years, he was diagnosed with an autistic spectrum condition, something that he refuted. He was said to have high functioning autism/Asperger's syndrome and depression. His condition meant that he felt unable to work. In 2012 he was assessed under section 2 of the Mental Health Act 1983 and he spent three weeks in the Campbell Centre an acute in-patient mental health service in Milton Keynes and was later discharged to the family home. In 2013 he moved to supported living and in 2015 after he had been assessed as no longer needing this level of assistance, he was supported to move into a flat to live independently. Around that time Adult D legally changed his name and he became estranged from his family. He refused to have any communication and sought an injunction after his family made attempts to contact him, including using the Salvation Army Family Tracing Service.

2.2 In September 2018 the police were called out because an online friend had been sent a suicide note by Adult D. The reason given for ending his life was that he believed he had been assessed as 'fit for work' by the Department for Work and Pensions (DWP) and he feared he would no longer be able to pay his rent or afford food after his benefits were stopped and he would become homeless. He was again assessed under the Mental Health Act 1983 and admitted to the Campbell Centre as an informal patient. In October 2018 he was discharged to the care of the Acute Home Treatment Team (AHTT) and two weeks later to the care of his GP. At the time his benefits had been reinstated and it was thought that the trigger for his suicidal ideation had been mitigated. A referral was made to adult social care before his discharge as he was thought likely to require care and support. A social care assessment was not completed. Ten months later Adult D was found deceased in August 2019 by bailiffs entering the property due to non-payment of rent.

3. Terms of Reference and Scope of the Serious Case Review

3.1 The criteria for a Safeguarding Adults Review (SAR)

Section 44 of the Care Act 2014 states that the Safeguarding Adults Board (SAB) must complete a safeguarding adults review (SAR) when an adult with needs for care and support (whether or not the local authority has been meeting any of those needs) if:

- there is reasonable cause for concern about how the safeguarding adults board, members of it or other persons with relevant functions worked together to safeguard the adult, and
- the adult has died and
- the safeguarding adults board knows or suspects that the death resulted from abuse or neglect (whether or not it knew about or suspected the abuse or neglect before the adult died)
- the adult is still alive and the safeguarding adults board knows or suspects that the adult has experienced serious abuse or neglect.

3.2 In the context of SARs, something can be considered serious abuse or neglect where, for example, the individual would have been likely to have died but for an intervention, or has suffered permanent harm or has reduced capacity or quality of life (whether because of physical or psychological effects) as a result of the abuse or neglect.

3.3 It was agreed by the Safeguarding Adult Review Panel that the review would follow specific lines of enquiry including:

- a) What analysis was given to the statements made by Adult D in relation to ending his life
- b) What the immediate discharge plan included and what thought was given to creating a multi-agency plan to support ADULT D
- c) How the post-discharge period was monitored
- d) Why the ASC referral was closed without any attempt to see ADULT D
- e) Any other questions arising after the first SAR meeting

4. Methodology

4.1 The individual agencies provided a chronology of information which was collated for initial analysis. Organisations provided Individual Management Reviews (IMR) using a report template. The information was used to facilitate a Learning Event for analysis and learning with practitioners. The purpose of the event was to identify key learning and to use the analysis and learning to inform this overview report.

5. Agency Involvement in the Safeguarding Adult Review

5.1 The review had engagement from senior managers and practitioners at the learning review sessions that included the organisations listed below:

- CNWL-MK Mental Health Service
- Milton Keynes Council Adult Social Care
- Thames Valley Police (TVP)
- The Department for Work and Pensions
- Guinness Trust Housing Association
- Adult ADULT D's GP

5.2 A joint multi-disciplinary adult mental health and social care service was managed by Central and North West London NHS Foundation Trust (CNWL) under a section 75 agreement¹ between 2012 and December 2016.

6. Engagement with Family

Information from ADULT D's mother and ADULT D's former partner

6.1 The MK Together Partnership is very grateful to ADULT D's mother and his former partner for agreeing to meet with the Independent Author and MK Together Programme Manager in December 2019. The following information was given at the meeting.

6.2 ADULT D's mother and his former partner described ADULT D as a vulnerable adult. He had been diagnosed with an autistic spectrum disorder with an Asperger's syndrome profile² and depression. ADULT D's partner told us that ADULT D had also been diagnosed with a personality disorder. At the time of diagnosis, Milton Keynes Council did not have a dedicated autism service for adults and did not offer supported housing specifically for people with autism, although ADULT D was provided with supported accommodation after a change in

¹ Section 75 of the National Health Service Act 2006. S75 is a partnership of equal control whereby one partner can act as a "host" to manage the delegated functions, including statutory functions of both partners who remain equally responsible and accountable for those functions.

² Autism is a spectrum condition. The May 2013 release of the new version of the Diagnostic and Statistical Manual of Mental Disorders (DSM V) subsumed Asperger's syndrome under the wider diagnostic label of autism spectrum disorder (ASD).

circumstances when he left the family home. Soon afterwards ADULT D ended all communication with his family.

6.3 ADULT D was described as embarrassed about his autism diagnosis and didn't want to talk about what was 'wrong' with him. He thought his mum saw him as 'disabled'. ADULT D was described as very articulate when he was in a calm state. However, he couldn't function with even the smallest amount of stress and when this happened, he couldn't express himself and at times he became self-destructive, for example punching himself in the head. ADULT D was extremely rigid in his thinking and his partner described how everyday mishaps would be seen by ADULT D as catastrophic.

6.4 ADULT D had informed his family of his homosexuality when he was 13 years old. His mother said they accepted this and it had not caused them any issues. The family had been living overseas when ADULT D returned to England to go to university aged 18 years. He was said to be 'a genius' with computers and had been a gifted child. At university, he had a breakdown and during his first term was unable to attend any lectures.

6.5 ADULT D's family described him as someone who could not think of the long-term consequences of his actions. Everything was either perfect or unacceptable to him. The family believe that his binary way of thinking meant that he was unable to make decisions in his own best interest when he became stressed. ADULT D was also described as someone who cared about other people and would always help out to the extent that he would often become exhausted and stressed.

6.6 ADULT D's partner said ADULT D felt that he was a burden and that he was trying to live his life as someone he couldn't be. ADULT D often talked about his views about when he wanted to die and at what age. ADULT D's mother and ex-partner said that there were so many people he could have reached out to but in their view, he made the irrational decision not to.

6.7 ADULT D's partner provided a copy of a letter that he had written to the DWP assessor dated 3 March 2017. The concluding sentence read, "ADULT D is not only an unsuitable person for any work environment but would be severely endangered by any finding that he was suitable for work or any work-related activities. Any such finding would put him at an immediate threat of suicide."

7. Chronology of professional involvement

7.1 The chronology of professional involvement includes significant events since 2012 as the context for detailed analysis of practice and to decision making between September 2018 and August 2019, which includes ADULT D's discharge from hospital and whether there were risk assessments and adequate support in place.

FIRST CONTACT

7.2 The first contact with ADULT D by any of the agencies was on 11 April 2012 when ADULT D's mother telephoned the adult mental health team as she was concerned about ADULT D who was becoming more isolated and his mental health was said to be deteriorating. A home visit took place on 15 April 2012 where ADULT D was reluctant to engage with the practitioner but eventually agreed to accept an appointment with the Milton Keynes Urgent Care Team - Assessment Short Term Intervention (ASTI) Team.

7.3 Between 11 April 2012 and December 2012 there were 199 contacts recorded between ADULT D and/or his mother and the adult mental health service, although some of the telephone calls and e-mails were about ADULT D, rather than face-to-face contact. These were often daily contacts. ADULT D was at first offered a mental health assessment during a joint visit by a CPN and a social worker. The outcome of this assessment was to arrange a MHA assessment³ which took place later the same day. His care was coordinated within the ASTI Team in 2012 before being admitted into the Campbell Centre for a further period of assessment. Following a stay as an informal patient, he was supported by the East Recovery Team.

FIRST CONCERNS ABOUT SELF-HARM

7.4 On 3 May 2012 ADULT D's mother contacted the mental health service to inform them that ADULT D had tried to hang himself the day before. She was concerned that ADULT D had said he would not live to reach his next birthday. A Mental Health Act 1983 (MHA) was considered but as ADULT D was reluctant to go to the hospital, a home visit was made on the

³ N.B. The distinction between a mental health assessment undertaken by mental health professionals including CPN, social worker and psychologists in order to build up an accurate picture of a person's needs and a formal Mental Health Act 1983 assessment, (MHA assessment) which is a legal process undertaken by an AMHP and two registered doctors where the person may be admitted to a hospital and detained under the Mental Health Act if they are deemed to be a risk to themselves or to others.

same day where it was decided ADULT D should see a mental health specialist. It was decided that a more person-centred approach was to see the ASTI Team consultant, rather than a consultant psychiatrist via the Mental Health Act 1983 (MHA) route and ADULT D consented to an appointment being made as part of a plan to engage with ADULT D.

7.5 The following day a joint home visit was made by a social worker and an Approved Mental Health Professional (AMHP) to assess whether a MHA assessment was required. The mental health service was in contact with ADULT D on 8, 9, 10, 11 and 14 May 2012. A Mental Health assessment was completed on 9 May 2012. It was noted in the Community Psychiatric Nurse (CPN) records that ADULT D continuously expressed a sense of hopelessness and worthlessness. He stated that he had chosen not to socialise. It is recorded that ADULT D stated that he had felt 'low' for the past ten years. The assessment recorded the risks including a history of taking an overdose three years earlier and ADULT D reporting that he had periodically tried to hang himself in his bedroom. ADULT D also discussed his social isolation, the fact that he was unemployed and his sense of futility. ADULT D could not identify any protective factors. The CPN opinion was that ADULT D was suffering from severe depression with unknown triggers for attempted suicide and that he may have undiagnosed Asperger's. ADULT D was offered an informal admission to the acute mental health service which he declined. A MHA assessment was requested and completed on the same day. The assessment concluded that there was no evidence of a mental disorder sufficient to warrant formal detention under the Mental Health Act.

MENTAL HEALTH ASSESSMENT AND DIAGNOSIS

7.6 In addition to the mental health assessments and Mental Health Act assessments and the ongoing support from the mental health services during May 2012, there were two other assessments completed; one by a clinical psychologist and the other by a consultant psychiatrist. On 16 May 2012, an urgent referral for an autism assessment was requested by ADULT D's mother because of the ongoing risk of suicide. The consultant psychiatrist appointment had already been made as a result of the home visit on 3 May 2012. The autism appointment was requested by the CPN following the home visits and assessments on 9 May 2012. Following the assessment, the consultant psychiatrist sent a letter to the GP stating he had made a diagnosis of a personality disorder with traits of schizoid personality disorder. The

consultant psychiatrist did not consider ADULT D to be clinically depressed or to have Asperger's syndrome.

7.7 The clinical psychology assessment process started on 23 May 2012. A face-to-face appointment took place with ADULT D who at the time consented to further assessments. He was taken to this appointment by the ASTI social worker. On 29 May 2012 ADULT D gave a new email address to the ASTI social worker stating that he wanted this to remain completely confidential and not to be disclosed to his family.

7.8 On 22 June 2012 ADULT D attended an appointment at the start of the assessment process with the clinical psychologist. The psychologist was a specialist in autism but at the time was based in the adult learning disability service. The psychologist reached an agreement with the Clinical Commissioning Group (CCG) to complete an urgent assessment outside the contracted arrangements. This was an example of good practice by the services. The referral was treated as urgent and bi-passed the waiting list. However, at the time there was no dedicated adult autism diagnostic service available to help ADULT D to understand what the diagnosis meant. The services in Milton Keynes were unable to provide any dedicated support immediately after the diagnosis or any ongoing care and support, other than by meeting his needs under the Community Care Act 1990⁴. ADULT D was extremely reluctant to be 'labelled' or to be seen as 'disabled'. A diagnosis of an autistic spectrum condition will pose a challenge to identity and self-concept.⁵ ADULT D was diagnosed with high functioning autism with a high IQ and low level of adaptive skills.

ADULT D'S REJECTION OF DIAGNOSIS

7.9 The records state that on several occasions professionals talked to ADULT D about his mother's concern for him and that she was desperately trying to get help. It was recorded that ADULT D did not want to be assessed and he did not accept the diagnosis of autism. The outcome of the clinical psychology assessment was a report stating that ADULT D 'was at risk of harm to himself and destruction of property if not supported in activities of daily living'. The report also included a request that ADULT D be considered for supported living. ADULT D

⁴ The Community Care Act 1990 was replaced by the Care Act 2014.

⁵ Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *Journal of Autism and Developmental Disorders*, 48(11), 3761–3772. doi: 10.1007/s10803-018-3639-1

was referred back to the adult mental health team. The health professionals working with ADULT D were all in agreement that ADULT D had high functioning autism/Asperger's and there was also agreement between professionals that this did not impact on his mental capacity.

7.10 The records show that ADULT D appeared to be struggling with issues of identity and self-esteem. He saw himself as being misunderstood, being 'different' and seeing the world in a different way to others, all of which are widely reported by adults diagnosed with autism in adulthood.⁶ Individuals with a diagnosis of high functioning autism are also reported to be more acutely aware of the difficulties they encounter during social interactions and therefore at greater risk of depression, low self-esteem and anxiety.⁷ This assessment had taken place without seeing ADULT D in person other than an initial meeting and relied on information provided by ADULT D's mother about his childhood presentation. ADULT D had attended the initial appointment (accompanied by the social worker) but did not attend the other appointments which formed part of the assessment process. ADULT D gave his reason for non-attendance being that he wanted professionals to make contact with him directly and not through his family.

7.11 On 30 June 2012 Adult Social Care received an e-mail from ADULT D's parents asking when he was to be provided with supported housing based on the recommendations in the psychologist's report.

7.12 Between 30 May 2012 and 25 July 2012 ADULT D's mother was in regular contact with the services to try to get supported housing for ADULT D. She had raised with the mental health services some of the risks ADULT D faced, including not eating; attending to his personal care; not talking to her and banging his head when he became anxious.

7.13 On 22 July 2012 ADULT D's mother requested another MHA assessment. The service acknowledged ADULT D's mother's concerns about the risks and a plan was put in place. The request for a MHA assessment was referred to the AMHP service. ADULT D met with the ASTI

⁶ Mental health services for individuals with high functioning autism spectrum disorder. Lake JK, Perry A, Lunskey Y *Autism Res Treat.* 2014; 2014():502420.

⁷ Social skills training for adolescents with Asperger syndrome and high-functioning autism. Tse J, Strulovitch J, Tagalakis V, Meng L, Fombonne, E J *Autism Dev Disorder.* 2007 Nov; 37(10):1960-8.

team the following day to discuss care and support. ADULT D was also reviewed by the AMHP service who decided a MHA assessment was not required.

ADMISSION FOR MHA IN-PATIENT TREATMENT

7.14 On 27 July 2012 ADULT D was admitted to the Campbell Centre under section 2 of MHA 1983. ADULT D had been visited at home but had remained mute throughout the assessment refusing to engage or to answer any questions. On admission, ADULT D continued to refuse to speak but later he explained that this had been a protest and he told the worker about his feelings about his mum doing everything for him, like cooking, financial provision and worrying about him living independently.

ADULT D's FAMILY MOVING ABROAD

7.15 Following his discharge on 24 August 2012 ADULT D raised a concern with the Acute Home Treatment Team. This is recorded as a 'safeguarding alert' and was referred to Adult Social Care. He said he was concerned that his family were moving abroad. The referral was passed to the community social work team for an assessment of his needs, follow-up and support.

7.16 On 3 September 2012 Adult Social Care completed their assessment. He was assessed as not being eligible for supported living. ADULT D had said that he did not want support and that he wanted to challenge the autism diagnosis. He stated that he was living in his family home with his parents paying all the bills and providing food. He was spending his time on his computer programming.

7.17 On 30 October 2012 ADULT D made his first claim for Employment and Support Allowance (ESA).

7.18 On 15 March 2013 ADULT D was no longer living in the family home and he moved into supported accommodation. There are generally different levels of support available in supported housing schemes including up to 24-hour care and support. ADULT D's level of support was much lower, reflecting his independence and between October 2012 and March 2013, he was in weekly contact with the care programme approach⁸ (CPA) co-ordinator with

⁸ The Care Programme Approach (CPA) is a package of care for people with mental health problems.

approximately 50 contacts recorded during that time and his needs were assessed monthly. Supported housing is not intended to be a permanent tenancy, but a stepping-stone to independent living and as such he was appropriately supported to find suitable accommodation as he was managing his shopping, cooking and he kept his flat clean and tidy. His mental health was also stable during this time.

7.19 On 7 October 2013 ADULT D changed his name by deed poll. ADULT D was by then refusing to have any contact with his family. On 12 March 2014, a mental capacity assessment was completed to determine whether ADULT D had the mental capacity to decide for himself whether to have contact with his family. There was no evidence available to the professionals to suggest that he did not have the mental capacity⁹ to make this decision although this was challenged at the time by his mother through her solicitor.

7.20 Between 2014 and January 2017 ADULT D contacted Thames Valley Police on 10 occasions because he believed that his parents were trying to locate and contact him. On 28 April 2016, ADULT D's mother made contact with the Salvation Army Tracing Service. The process was slow and eventually on 19 January 2018, the police informed the Salvation Army that ADULT D had been in contact with them and that he did not want any contact with his family or his details to be disclosed to them.

CPA SUPPORT

7.21 Between 2012 and February 2016 ADULT D had been under the care programme approach (CPA) and during that time his mental health had been stable and he was regularly reviewed by the multi-disciplinary team (MDT). ADULT D repeatedly asked to be discharged as he reported feeling happy and stable and with no thoughts of suicide. ADULT D was discharged on 12 February 2016.

7.22 A month before that on 11 January 2016 ADULT D had moved to an independent living flat managed by a social landlord. Although ADULT D was still under the care programme approach, the housing association was not informed by either the mental health service or the supported accommodation service about where he had been residing before his new tenancy began or his history of attempted suicide. Although his mental health had been stable

⁹ Under the MCA 2005 there is a presumption of capacity, section 1(2) states: "A person must be assumed to have capacity unless it is established that s/he lacks capacity."

for some time when he moved and it would have been important to only share information that was relevant and proportionate, had his history of suicidal ideation been made available to the social landlord, it would have been used to alert them to his potential vulnerability and a marker would have been placed on his account so that if his rent went into arrears they would make inquiries into his safety and welfare and they would also have contacted his next of kin.

7.23 The mental health service made contact with ADULT D after his discharge from the CPA support. On 17 February 2016, he was seen and he stated categorically that he felt safe and well and could manage without any therapeutic intervention.

7.24 Between 12 February 2016 and 13 September 2018 there were three contacts between ADULT D and the ASTI team. On two separate occasions, ADULT D telephoned to say he was feeling distressed because his mother was trying to make contact with him. On 24 February 2017 ADULT D contacted the services because he reported feeling stressed and depressed about a 'fitness for work assessment'. He denied any thoughts of self-harm or suicide but sought 1:1 counselling. A referral was made to MIND and a letter written to ADULT D's GP. On 3 March 2017 ADULT D attended a work capability assessment and following this he was placed in the 'work-related activity group'. The letter written by his partner was handed to the assessor and placed on the DWP file. At the learning event held for practitioners and managers, the DWP acknowledged that for ADULT D the term 'work-related' might have been taken literally. The word 'group' does not mean a group of people who meet, but a one-to-one meeting between ADULT D and a work-coach. This broad group of claimants is applied where the DWP consider someone *may* be capable of work *at some time* in the future. The benefits system is underpinned by 'claimant conditionality' which has been extended to all disabled people in recent years with the introduction of welfare reforms. This means that there is an expectation that the work coach will actually 'see' the claimant and that they will be expected to take appropriate steps to find work. However, this did not mean that ADULT D would have been expected to go straight into a work environment, but he may have been asked to do very limited voluntary work for example.

ADULT D's ESA SUSPENDED

7.25 ADULT D failed to attend his next work capability assessment in April 2018. ADULT D sent the DWP a BF223 (a form to explain the reason for his failure to attend) which stated that he couldn't go to the office. It took until 15 August 2018 before the DWP sent a text message to ADULT D to inform him that the 'good cause' for the failure to attend the WCA was not accepted, although he remained in receipt of benefits during that time. He was also informed of his right to ask for a mandatory review of the decision. On 20 August 2018 ADULT D asked for a mandatory review. On 21 September 2018, DWP informed ADULT D that there was no change to their decision and this ended the employment support allowance (ESA) claim.

7.26 ADULT D had by then been admitted to the Campbell Centre. (13 September 2018 to 5 October 2018). The police had taken him to A & E having been called out when an online friend informed them of a lengthy suicide letter where he stated that he intended to take his own life on 19 September 2018 because he had been informed that was the date when his claim for benefit would end.

7.27 On 25 September 2018 a support worker at the Campbell Centre tried to assist ADULT D to reinstate his benefits. They took an ESA1 (claim form) printed off the internet as well as a Med 10 (a hospital certificate form which is issued to inpatients if treatment continues for more than seven days) to the DWP office on ADULT D's behalf. On 27 September 2018, the new claim was disallowed because it was within 6 months of his failure to attend the work capability assessment on 4 April 2018.

7.28 On 4 October 2018 a letter was received by DWP from the support worker asking for the original decision to be reviewed given ADULT D's mental health concerns. A supporting letter was also sent by the consultant psychiatrist regarding the work capability assessment in which ADULT D declared that work made him feel suicidal. On 5 October 2018, ADULT D's benefits were reinstated. The original 'failure to attend' decision was allowed as a 'good cause'. The original claim was reopened with a start date from 5 April 2018 and the benefits were backdated. The DWP informed ADULT D that he would not need to be sent for a further assessment until after his discharge from hospital.

7.29 Whilst ADULT D was an inpatient on 25 September 2018 an urgent adult social care assessment was requested with a copy of ADULT D's statement to end his life appended to

the request. A social worker assistant was not allocated for two months until 26 November 2018. This delay is acknowledged by the service to be completely unacceptable.

7.30 On 5 October 2018 ADULT D was discharged from the Campbell Centre with support from the Acute Home Treatment Team (AHTT). On 14 October 2018 ADULT D attended an appointment with AHTT and a plan was agreed to discharge him back to the care of his GP once the benefit back payment was received.

7.31 On 18 October 2018 ADULT D attended another appointment with the AHTT. He told them that he had received a letter stating that he was in the 'work-related activity group' and that he would need to attend the benefits agency regularly. ADULT D stated that work made him stressed and anxious and he had decided he 'will never work in his life' and 'would rather die'. He asked for a supporting letter to request he be exempted from work. The AHTT practitioner had not met ADULT D before and suggested asking his GP who knew him better.

7.32 Suicide risk assessments were carried out on 13 September; 5 October and on 18 October 2018. Risk assessments cover the risk to self and others; mood; suicide risk and depression. The depression and anxiety tools completed before discharge were PHQ-9 and GAD-7¹⁰. The hospital discharge had been based on the risk of suicide being in part mitigated because the benefits were reinstated. The practitioner explored ADULT D's feelings and made contingency arrangements for if he had any suicidal thoughts. ADULT D stated that his only worry was the expectation that he attended the Jobcentre regularly. On 12 November 2018 DWP sent ADULT D an invitation letter to attend a work capability assessment on 3 December 2018. The DWP has confirmed that this was a system generated letter triggered by the recent review of his claim and confirming his entitlement to ESA. This caused ADULT D anxiety and distress and although the 'invitation to attend' letter provides a telephone number to contact the DWP if the person has any concerns, ADULT D sought help from other sources.

7.33 On 15 November 2018 ADULT D was seen by his GP. The GP noted his recent discharge from the Campbell Centre due to suicide risk. ADULT D stated that he had received a letter from DWP asking him to attend for a medical assessment on 3 December 2018. He requested a letter from the GP so that he could ask for a home assessment. He was said to be very

¹⁰ The PHQ-9 and GAD-7 are designed to facilitate the recognition for depressive disorders and anxiety disorders respectively. These are the national standard measures routinely used by GP's, therapists and psychiatrists as screening tools. The scoring for both measures helps people to ascertain how severe the issue is.

worried that going to the city centre would set off a severe anxiety attack and he would be unable to attend. The GP agreed to do a 'to whom it may concern' letter. There is no evidence that the letter was collected from the surgery. ADULT D failed to attend the work capability assessment.

ADULT D OUT OF CONTACT

7.34 From November 2018 there were several failed attempts by three agencies to contact ADULT D. These included a social work assistant who was making the first contact by telephone following the urgent request in September 2018 for an ASC assessment, the DWP home visiting service who were following up the failure to attend the work capability assessment and the Housing Association who were following up on rent arrears. These visits were uncoordinated between the three agencies who do not routinely work together and would therefore not usually communicate with each other. The lack of communication, or, in the case of the Housing Association, the lack of any background information having been made available to them, meant that none of the agencies had cause to raise any concerns about ADULT D's welfare and safety. It was not until 11 April 2019, that the Housing Association issued a notice of eviction for non-payment of rent. ADULT D had until this point been seen as a 'model' tenant. Once the notice of eviction had been sent in April 2019 and up until August 2019 there were four home visits attempted by the housing association, eight letters sent, three emails and two text messages. There were numerous telephone calls attempted but by then the phone had been disconnected.

7.35 The DWP visiting team made a home visit on 18 January 2019. The referral was closed by the DWP visiting team after the unsuccessful attempt to see ADULT D. DWP records state that the visiting officer noticed the visit notification letter was still in a mailbox along with other mail. A second appointment letter was sent for a home visit on 24 January 2019. The visiting officer noticed the original visit letter was still in the mailbox along with other mail.

7.36 The social work assistant from the Adult Social Care Service had tried to telephone ADULT D on 3 December 2018 and a second attempt was made four days later on 7 December 2018. Voicemail messages were left on both occasions. On 7 December ADULT D's mother called the social worker to say that they had the wrong number and they were calling her number, not ADULT D. On 7 December 2018, a voicemail message was left for ADULT D to arrange a

meeting. On 10 December the social work assistant wrote to ADULT D to offer him an assessment and gave him until 31 December 2018 to reply or they would close the case. On 21 December 2018, there was a final attempt to call ADULT D, but the number was unobtainable.

7.37 Given that the urgent referral made by the Campbell Centre to ASC on 25 September 2018 for a review or an ASC assessment that had been sent with a copy of ADULT D's statement to end his life appended, the complexity and the level of risk should have led to the case being allocated to a qualified social worker. On 3 January 2019 the social work assistant had a supervision session where the lack of response by ADULT D to the letter offering an adult social care assessment was discussed and the advice was to contact the AMHP service to confirm ADULT D's address and that if the address on their recording system was the same, the case was to be closed. The case was closed without having made a home visit.

7.38 Adult social care have acknowledged that they should have made the assessment whilst ADULT D was still an inpatient at the Campbell Centre. As this did not happen they should at least have made an early home visit to ADULT D. There was no record that the adult social care worker contacted the Acute Home Treatment Team or the Campbell Centre to find out background information about ADULT D. In response to what has happened adult social care services have now made changes to their procedures and all staff are now directed to make a home visit to any adult with care and support needs and safeguarding concerns. If on a second visit they are still unable to get a response they will refer the matter to their line manager and make a referral to the police for a welfare visit. The lack of information and the absence of any communication between the agencies who visited ADULT D at the end of 2018 and during 2019 meant that no-one involved was curious enough to follow up with the other agencies, check with neighbours or contact the housing association tenancy support officers who might have confirmed that ADULT D had not been seen and therefore triggered a welfare check from Thames Valley Police.

8. Findings and Analysis of the Investigation

8.1 Asperger's syndrome is a very complex and often misunderstood disorder. The term no longer exists as a formal diagnosis and is now subsumed under the term 'autism spectrum

disorder'. The term Asperger profile is sometimes used to differentiate from the autistic spectrum disorder wider umbrella term. Individuals with an Asperger profile are in themselves unique and the profile is different for each person, which can make diagnosis difficult. Having an Asperger profile involves neuro-biological differences in how information is processed and integrated by the person and this can profoundly impact on the person throughout their life. They are often misunderstood and misjudged. Practitioners often incorrectly assume that articulate people with autism are capable in areas in which they struggle, whilst those with less verbal skills are often incorrectly assumed to be lacking in skills, 'strengths', ability or potential. This context is necessary to understand and to learn the lessons from this SAR.

What analysis was given to the statements made by ADULT D in relation to ending his life?

8.2 A study of people with Asperger's syndrome reported in The Lancet Psychiatry in 2014 found that people with high functioning autistic spectrum disorder were significantly more likely to report suicidal ideation or plans or attempts at suicide if they also had depression¹¹.

8.3 ADULT D disclosed to a social worker and an occupational therapist in 2012 that he had attempted an overdose in 2008 following a traumatic incident. ADULT D was encouraged to talk about the incident which was thought to have triggered a suicide attempt, but he would not disclose what had happened. At around the same time in 2012 ADULT D told a CPN that one of the reasons he wanted to die was because he was, "wired up wrong". The CPN encouraged ADULT D to elaborate and ADULT D stated that "he is not designed for the planet." The CPN demonstrated appropriate professional curiosity and several attempts were made to understand this event during 2012 and 2018 during the mental health assessments and the MHA assessments.

8.4 On 13 September 2018 Thames Valley Police responded to a call they received from a 'friend' ADULT D had met on a gaming website who explained that he had seen a 14-page document that was e-mailed by ADULT D to 40 people informing him that he intended to take his own life on 19 September 2018. ADULT D agreed to be taken to Milton Keynes University Hospital by the police to be seen by a mental health professional. The police used persuasion

¹¹ Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. Sarah Cassidy, Paul Bradley, Janine Robinson, Carrie Allison, Meghan McHugh, Simon Baron-Cohen; Lancet Psychiatry 2014; 1: 142–47

to get ADULT D to attend A&E for his safety. This was good practice as the officer used the least restrictive option available to move ADULT D to a place of safety.

8.5 ADULT D was assessed under the Mental Health Act 1983 on 13 September 2018 following his admission via A&E, when ADULT D agreed to an informal admission to the Campbell Centre. The acute mental health service was fully aware of the lengthy suicide note where ADULT D stated that he was planning to take his life in 5 days. The professionals involved with ADULT D recorded that they had explored at length his very strongly held beliefs in the right to choose euthanasia. The staff on the ward were fully aware that in the document ADULT D stated that a reason he wished to end his life was the notification that he would be losing his benefits because he had not attended a 'fitness for work' assessment. It was also recorded that ADULT D had a strongly held belief that he should not have to work for a living and that the state should pay him to stay at home. Because the suicide document gave his benefits being stopped as the main trigger, the mental health worker made every effort and succeeded in getting the benefits reinstated and ADULT D was not discharged from hospital until these were in place and a back payment was being processed. During his admission, ADULT D repeatedly asked to be discharged. He was an informal patient and he was free to leave the ward whenever he wanted. A mental capacity assessment had been carried out on his admission to determine that he had the capacity to consent to his informal stay. It was therefore not necessary to request a deprivation of liberty safeguards assessment.

8.6 ADULT D did not present on the ward with a major mental health disorder although he had previously been diagnosed with depression. The assessment and the interaction with ADULT D focused on his history of suicidal ideation. ADULT D had talked about being in favour of euthanasia. He told staff that he intended to pursue changes to the law and he was in contact with a doctor in The Netherlands where he believed euthanasia was lawful. ADULT D denied any suicide plans whilst he was an inpatient. ADULT D was supported by the staff and because it was understood that the most recent trigger for his intended suicide plan had been resolved when the benefits were reinstated and therefore the risk of suicide had been partially mitigated.

8.7 The risk of suicide was analysed and the staff had discussed with ADULT D his feelings and the reasons he held his belief in euthanasia and why he felt that his life should end. It was important for the MDT to balance the risks and protective factors. Despite ADULT D's view

that he did not have care and support needs, there were questions about his inability to protect himself and there was an absence of resilience or protective factors. It was reasonable to expect that to achieve a robust and holistic discharge plan, ADULT D should have been seen by adult social care and offered an assessment whilst he was still an inpatient at the Campbell Centre. The staff at the Campbell Centre followed ADULT D's wishes when he consistently refused to consent to his family being involved in his care and treatment. The professionals involved accept that it is particularly important where the risk of suicide is thought to be high to attempt to involve family members because family and social cohesion can help to protect against suicide. There are 'Think Family'¹² initiatives within the Trust. The staff spent time trying to get ADULT D to understand that his family were concerned for him but ultimately, the staff could not breach patient confidentiality.

What the immediate discharge plan included and what thought was given to creating a multi-agency plan to support ADULT D

8.8 There was no effective multi-agency joint planning on ADULT D's discharge from the Campbell Centre. It is now recognised by the agencies that there were gaps in aftercare planning between health and social care services at the time that have since been addressed. There is now a link worker involved directly in all mental health discharges that require input from adult social care and the adult social care service manager attends all the 'bed management' meetings.

8.9 ADULT D's immediate discharge plan was to provide a supported discharge with the acute home treatment team. A handover meeting took place on the ward on 5 October 2018. ADULT D was asked to consent to his treatment. The plan was for ADULT D to make contact with AHTT within two days of discharge, for him to attend an appointment on 9 October and for a referral to be made to the psychology service (IAPT)¹³ for psychological therapy. Emergency contact details were provided for out of hours services. The plan was to provide ADULT D with support from AHTT for two weeks and discharging him back to the care of his GP.

8.10 The serious incident investigation carried out by the acute mental health service (CNWL), in August 2019 identified that the staff from the home treatment team had not seen the 14-

¹² Social Exclusion Unit Taskforce (2008b) Reaching out: think family, London, Cabinet Office.

¹³ Improving Access to Psychological Therapies

page suicide letter. Had they been aware of this information, the referrals to 'Live Life'¹⁴ and the GP might reasonably have been expected to have been followed up before the case was closed. No evidence was found that a referral was made to IAPT. If any of the actions or the referrals had been made it would have improved the opportunity to help make an effective difference. It is recognised that both actions fall below the standard of care that is to be expected.

8.11 The risk assessment was regularly monitored and discussed by the acute mental health services multi-disciplinary team (MDT) on the ward and they did provide a person-centred risk assessment. A referral was made for a social care assessment, but this was not completed. This may or may not have resulted in services being provided to ADULT D because when he had been assessed in 2012 and 2015 he had stated he did not have 'needs' that could be met through adult social care services.

8.12 Whilst ADULT D was an inpatient in September 2018, benefits were identified as a significant trigger in his suicidal ideation. The staff at the Campbell Centre pursued the benefit claim with the DWP and were successful in getting his ESA reinstated and backdated. They also made sure that this happened before he was discharged and DWP reviewed their decision within one day. This was good practice.

8.13 ADULT D suffered from debilitating anxiety about having to go into the city centre to meet with the work coach at the DWP. When the computer-generated system sent an invitation letter to ADULT D for an appointment on 3 December 2018, this was a trigger for ADULT D's anxiety and stress. The Home Treatment Team dealt with this by directing ADULT D to his GP for support. This raises questions about whether it would have been appropriate for the Home Treatment Team to intervene and to liaise with the GP and to inform DWP about ADULT D's fear of an anxiety attack if he visited the city centre. They should have taken a more proactive approach and alerted the GP and the DWP. Professionals who knew ADULT D were all clear that ADULT D did not want to work and that he had a strongly held belief that he should be paid benefits to enable him to stay at home. Equally, 'conditionality' is inbuilt into the welfare benefits system that requires claimants to engage with DWP and for some,

¹⁴ Live Life is a charity based in Milton Keynes who work alongside people who may be feeling isolated and need help to access support.

if not all of those claimants in the work-related activity group to take reasonable steps to prepare for work in the future. One of the lessons from the SAR is that assistance with employment issues for people with high functioning autism can be extremely effective.

How the post-discharge period was monitored

8.14 Studies have shown that the risk of suicide is higher immediately after discharge from in-patient mental health wards than at any other time in a person's life. The National Confidential Inquiry into Suicide and Homicide showed that a quarter of all suicides occur within the first three months of discharge.¹⁵ It is known that the risk factors in the post-discharge period are higher among men under 45 years and for those with a diagnosis of depression and/or a past history of deliberate self-harm.

8.15 ADULT D attended all three of the arranged appointments with the acute home treatment team on 9, 14 and 18 October 2018. He continued to say he would not die by suicide although he also continued to talk about his belief in euthanasia. In his home treatment discharge meetings, he stated that he was anxious about a letter instructing him to attend a 'work-related activity' group. The practitioner used the depression and anxiety tools, PHQ-9 and GAD-7 and explored his thoughts and discussed a contingency plan with ADULT D in which they identified individuals he would seek support from, in addition to being given the Crisis Line contact details and advised to visit A & E in a mental health crisis.

8.16 A month later on 16 November, ADULT D contacted the Campbell Centre about his benefits, although he had been discharged back to the care of his GP at this point. He said that he had been referred to 'Live Life' for social support and said that he was 'okay' other than his benefits. Because ADULT D indicated that he had been referred to community support with the one concern that he had previously raised in October 2018, the unmet need was not identified because Live Life was thought to be providing support with benefits. Although ADULT D was offered information about where to seek help in a crisis which was good practice, nothing had fundamentally changed in ADULT D's life. He continued to state that he was anxious about having to attend DWP meetings and assessments and his fear of being made to work.

¹⁵ Department of Health (2001) Safety First: Five Year Report of the Confidential Inquiry into Suicide and Homicide by People with Mental Illness. London: Department of Health.

8.17 ADULT D was known to have long-held beliefs about topics such as working for a living and about euthanasia. Research¹⁶ shows that people with high functioning autism with an Asperger's profile often experience cognitive rigidity. Because at the time there was no service in Milton Keynes to help ADULT D to come to terms with a diagnosis that he profoundly disagreed with, professionals who worked with ADULT D acknowledged his 'quirky' personality. They respected his confidentiality and they developed a trusting relationship with him. The professionals focussed on getting the benefits reinstated. The home treatment service was aware of ADULT D's anxiety about attending DWP but signposted to the GP.

8.18 Research shows that suicide in the post-discharge period is more common among those with poor social support.¹⁷ The referral to adult social care for an assessment should have been completed before ADULT D was discharged and should have considered the lack of contact with family and his level of social isolation.

Why the ASC referral was closed without any attempt to see ADULT D

8.19 ADULT D was allocated an experienced social work assistant on 26 November 2018, although given the complexity of the circumstances this was not appropriate. The worker attempted to make contact with ADULT D on 3 December 2018 via his mobile telephone to arrange a time to meet. Despite a further five attempts via phone and letter, the worker was not able to make contact with ADULT D. The social work assistant did not attempt to visit ADULT D at his home address. The service accepts that a home visit should have been attempted even if ADULT D had not answered the door. A referral to the Police for a joint safe and well visit could have been made at that point. Workers are now directed to visit a person's home if they cannot contact them by telephone and there are policies and procedures in place to prevent this from happening in the future.

Other issues raised

8.20 There were no appropriate services available to ADULT D to understand the diagnosis he was given at the age of 21 years. This is a time of life when he would naturally have been

¹⁶ Elizabeth Roberts, PsyD; Cognitive flexibility: Keep thinking limber and flexible; July 25, 2017

¹⁷ Appleby, L., Shaw, J., Amos, T. et al (1999b) Suicide within 12 months of contact with mental health services: National Clinical Survey. BMJ, 318, 1235–1239

trying to develop his own identity and live independently. According to the National Autistic Society, 70% of adults who are diagnosed after childhood say they don't get the help they need¹⁸. In discussions recorded with mental health practitioners, he had said that he was, 'wired up wrong'. ADULT D may have struggled with his 'difference' and as he became estranged from his family, this increased his vulnerability. Under the Autism Act 2009 ADULT D was entitled to an assessment of his needs. The NICE Guidance state that where, 'adults with autism without a learning disability who are having difficulty obtaining or maintaining employment, professionals should consider an individual supported employment programme. This should typically include, help with writing CVs and job applications and preparing for interviews, training for the identified work role and carefully matching the person with autism with the job, advice to employers about making reasonable adjustments to the workplace and continuing support for the person after they start work.'¹⁹

8.21 At the time of ADULT D's discharge from the Campbell Centre, adult social care was experiencing a high demand for support and there was a waiting list for allocation to a social worker. When ADULT D's referral for an adult social care assessment was made in September 2018, a Mental Health and Autism Social Care Team had recently been established but they were experiencing difficulties in attracting social workers and the team was carrying a high level of vacancies. The recruitment and retention of experienced social workers at the time were not due to a lack of financial investment in Milton Keynes, but recruitment was then and remains a national challenge. There are currently four social worker vacancies and four social work assistant vacancies and despite a recent recruitment campaign running on social media, attracting social workers, particularly AMHPs remains a problem. The demand for the service has increased and there is currently a long waiting list for the services.

8.22 ADULT D had a legal entitlement to an adult social care assessment under the Autism Act 2009. This should have been completed whilst ADULT D was an inpatient. ADULT D would not necessarily have been entitled to any support services and especially if he believed that he did not require support and could manage independently. The Care Act 2014 does not use the word 'vulnerable' which is considered by some to be disempowering but encourages

¹⁸ NAS: A report from the All Party Parliamentary Group on Autism on understanding, services and support for autistic people and their families in England 2019

¹⁹ Autism spectrum disorder in adults: diagnosis and management

NICE Clinical guideline [CG142] Published date: 27 June 2012 Last updated: 18 August 2016

practitioners to consider an individual's strengths and resilience. It would be reasonable to expect that a thorough and robust assessment should have taken into account ADULT D's lack of resilience, his rigidity of thinking and his anxiety about leaving the flat.

8.23 Health and adult social care services undoubtedly faced a dilemma because ADULT D's mother had instigated referrals to the services to try to get a diagnosis and to secure help and assistance for her son. However, ADULT D would not consent to the mental health service communicating with his parents and he specifically and consistently asked them to respect his confidentiality. If they had failed to do this, they would have left themselves open to criticism and potentially legal action. ADULT D was in telephone contact throughout with individual practitioners at the services even when his 'case' was formally closed to the services.

8.24 In March 2014 ADULT D's mother had requested through her solicitor to have contact with her son and to be informed about his wellbeing. Three mental capacity assessments had been carried out to ascertain ADULT D's ability to decide what contact he should have with his family and a separate mental capacity assessment was also carried out to ascertain whether he could consent to being admitted to an acute hospital ward. The Mental Capacity Act 2005 Code of Practice provides guidance to professionals who are legally required to have regard to the relevant guidance. Mental capacity assessments are decision and time-specific. Under the code of practice, the staff asked ADULT D about three decision specific areas. On separate occasions, specific questions about whether his family should have information about his well-being. Another assessment asked whether ADULT D would or should have contact with his family. On admission to hospital, he was asked to give consent to his accommodation. None of the professionals expressed any doubt at the time of assessments, that ADULT D had the capacity and that he could make decisions for himself. There was no evidence to the contrary. Despite this, an independent advocate was appointed by adult social care. ADULT D did consent to an advocate's report being forwarded to his mother's solicitor instead of the capacity assessment.

8.25 The two-stage test of mental capacity requires that there has to be evidence of "an impairment of, or disturbance in the functioning of, the mind or brain". The consultant who conducted the mental capacity assessment was of the opinion that ADULT D's high functioning autism did not impede on his mental capacity and he, therefore, did not meet the

first test as defined in the Mental Capacity Act. The mental capacity test has a low bar and it is intended to empower individuals and to assist them in making their own decisions, even if they make unwise decisions. Although ADULT D had a high IQ and was highly intelligent, he did appear to have difficulty understanding social conventions and reading social cues. His family and partner talked about his need for things to be perfect and his 'all' or 'nothing' thinking. As a result, complicated feelings may have confused him.

8.26 It is acknowledged that services to support people with autism in Milton Keynes could have helped ADULT D to understand his different view of the world. ADULT D did have his care coordinated within the mental health service under the CPA approach, following his discharge from hospital in 2012 and during times when there were no concerns about his acting on his suicidal thoughts. The services were aware of ADULT D's parents' ongoing concerns for their son's health and welfare and his general wellbeing. It was appropriate for statutory agencies to be proactive in their attempts to engage and support ADULT D, but once it had been identified that his primary needs were associated with his autism, ideally he should have been transferred to an appropriate autism service rather than coordinated within mental health services, but this was not a service that was available at the time. This was a system weakness rather than a practice issue.

8.27 There was some good and effective practice from professionals involved in ADULT D's care. The determination to ensure that ADULT D's benefits were reinstated were pursued and he was not discharged until after the payments had been made. Professionals who knew ADULT D have been saddened and distressed by his death.

9. Progress and Lessons Learnt

9.1 The main lesson learned from this safeguarding adult review is a focus on how professionals should engage with adults with a hidden disability such as high functioning autism. Generally, the clinicians working with ADULT D acknowledged the traits of Asperger's and ADULT D's experience of living with those traits, although ADULT D rejected the diagnosis. ADULT D was offered a second opinion, but he did not attend the meeting. The late diagnosis meant that ADULT D did not receive professional intervention that might have helped him to

address some aspects of his life such as his rigid thinking, social isolation through his anxiety about face-to-face contact and his fear of having to go to work. ADULT D's anxiety and depression were mental health conditions that should have been addressed either through primary care or the acute mental health services and yet attempted suicide was the reason for mental health service intervention. On his discharge from the hospital, he was risk assessed and discharged back to GP primary care as not requiring acute mental health services. This gap in provision has since been addressed.

9.2 The practitioner's focus was on the issues that ADULT D presented and they respected his request for confidentiality and his wish to be independent of his family. Acute mental health services were not equipped to identify the underlying everyday struggle that was ADULT D's life. The Acute mental health services are designed to help people at a time of crisis who are diagnosed with mental illnesses such as depressive disorder, bipolar disorder and schizophrenia. Whilst it is vitally important that staff on acute mental health wards are trained to understand autistic spectrum conditions (ASC), the ward environment where other patients may be in a state of distress can severely impact on patients with an ASC. Adult social care assessments often focus on the individual's ability to carry out practical tasks of everyday living. ADULT D was able to shop and cook for himself and to keep his flat clean and tidy. There was a reluctance to consider the intervention required to address ADULT D's autistic traits and a failure to consider how a hidden disability like autism can impact on a person's everyday life. ADULT D struggled with social skills, sensory overload and isolation. This was very difficult to address because of ADULT D's reluctance to be labelled and his insistence that he did not require practical help or support.

9.3 Milton Keynes Council and Milton Keynes Clinical Commissioning Group have acknowledged that there were gaps in services for adults at the time for adults who are not diagnosed with autism in childhood. They now have an Autism Service that was developed in partnership between health and social care and this provides assessment, diagnosis and some post-diagnostic support for people aged 16 and over. The service now provides psychology, speech and language therapy and occupational therapy alongside social care.

9.4 As a direct result of the learning from this SAR there is now a link worker employed to work on the acute mental health hospital ward who is responsible for coordinating social care assessments before discharge, for any patient who needs the input of adult social care. There

are currently no delays for inpatients at the Campbell Centre receiving ASC assessments prior to discharge. The team now prioritises referrals received from the Campbell Centre. Adult Social Care acknowledges that the failure to complete an assessment for ADULT D was unacceptable. The service manager now attends all bed management meetings and has an overview of who will require an adult care assessment and when they will be discharged.

9.5 The Integrated Autism service now employs four specialist employment workers who link with the DWP and who work with service users to help them into employment.

9.6 The lessons learned around patient confidentiality and the right of patients to decide not to involve their family were very challenging in this SAR. ADULT D was very explicit that he did not want his family to be informed about his care and treatment. The mental health services have responded to this by making sure that they are now clear that they know who the significant people are in a patient's life. With each contact, they double-check to ensure where they can, patients agree to have family and friends informed and for this to form part of their support when they are discharged from the hospital.

9.7 DWP now has a different national system in place as ESA has now been replaced in many areas of the country with Universal Credit. DWP acknowledges that ESA had a different delivery model when ADULT D made a claim. ESA is managed through a national telephone network and he would have been put through to staff who did not know him when he made contact by telephone. Under Universal Credit, the model of delivery is that a case manager and a work coach now have a 'caseload' and when the claimant telephones DWP it automatically connects to their designated case manager. The model is intended to build a relationship based on trust and knowledge about the claimant and for the approach to be based on problem-solving and finding out what the barriers are to a person finding successful employment.

9.8 The DWP acknowledges that a system generated letter to ADULT D and the possible misinterpretations around the words 'work-related activity group' may have been challenging for ADULT D. Other learning from this safeguarding adult review is that people with autism have difficulty with language and communication and it is common for them to make a literal interpretation of the terms that are used. The department is keen to work closely with safeguarding adult boards. As part of the review the DWP has acknowledged that whilst they

may not be part of any multi-agency discharge planning arrangements, nor do they provide a counselling service, by working more closely with mental health and other professionals including GPs, this would create a better flow of information about vulnerable claimants so that the work coaches and case managers can exercise judgement on compassionate grounds, make home visits and telephone contact where necessary. The DWP has now recruited 10 senior partnership leaders who have safeguarding work as a priority as a temporary arrangement in response to the COVID-19 pandemic. A further 25 full-time safeguarding leaders are planned and should be recruited by mid-September. Their primary role will be to work in partnership across geographical areas to improve safeguarding arrangements by working with the local authority, the NHS and the police. DWP is also aware that there may be claimants that they could potentially 'signpost' to other services. The learning from this forms one of the main recommendations of the SAR.

9.9 Information sharing between agencies, especially information that could have been shared from supported housing and the mental health service to the housing association where ADULT D moved into independent living would have ensured that there was a 'flag' on the system in case rent wasn't being paid. The tenancy support they provide would have been alerted sooner to the fact that no-one had seen ADULT D during the lengthy period after his death.

9.10 It is the responsibility of all services to be curious and to follow up on indicators of potential concern such as post not being opened or messages not being returned. Some services need to work with families who can and often do provide a great deal of informal care, raise concerns and complaints and often make the services aware of the deterioration in a person's health. It is important that where someone is as clear as ADULT D was about family involvement, they respect the person's direct instructions where a person has the mental capacity to decide. ADULT D had mental capacity, was not self-neglecting and he was engaged with services. The mental health service in Milton Keynes is developing a peer model which will mean that where families for whatever reasons are not able to be involved there will be an alternative service of contact and support.

10. Conclusion

10.1 The SAR highlighted examples of good practice. The Thames Valley Police officer persuaded ADULT D to attend A&E as a place of safety using the least restrictive option.

10.2 DWP reviewed a decision within one day and reinstated ESA and backdated the benefit once they were aware of the circumstances of the hospital admission.

10.3 The multi-disciplinary team worked well and joint working and joint practices from within the team were effective. The mental health services maintained contact with ADULT D over a lengthy period and that included times where his mental health was stable and he stated that he was happy and was not having suicidal thoughts.

10.4 There were also examples of where things did not go well. There was no multi-agency discharge plan. The communication between several agencies was poor. DWP and the housing association have not routinely been a part of the safeguarding arrangements. Lack of communication between the mental health service and adult social care led to delay. The subsequent failure to undertake an adult social care assessment when ADULT D was discharged from the hospital should not have happened.

10.5 The lack of information about ADULT D's reason for admission to hospital and the lack of a co-ordinated response, when he was referred to his GP for assistance because of his anxiety about attending a DWP interview, highlighted how ADULT D fell between the services and failed to get the assistance he needed. There was a high reliance on ADULT D to self-refer to the GP.

10.6 The DWP acknowledges that the claims process generated a computer system letter of invitation for an interview without a person checking on the circumstances of the individual.

10.7 The SAR has highlighted the principle of conditionality in the welfare benefits system. To remain eligible to claim ESA, claimants are required to participate in the 'work capability assessment', which ADULT D was unable to do. He was required to show 'good cause' for failing to engage. Professionals acting on his behalf later provided the evidence of 'good cause' and so his claim was reopened. However, ADULT D was still required to participate in the work capability assessment process and another appointment was scheduled. The

Department's guidance has recently changed. Where DWP is unable to make contact with an individual after two ineffective safeguarding visits, additional checks will be put in place. The claim will not be automatically closed but escalated to a senior safeguarding lead who will liaise with the NHS, police and adult social care. Under the new guidance, ending benefit entitlement will become the last resort. No-one can say what difference it would have made if these changes had been in place at the time of ADULT D's death. The 'good cause' for non-attendance had been accepted for the previous work capability assessment but ADULT D was required to attend future appointments on discharge from hospital as a condition of claiming ESA.

10.8 The SAR has highlighted the major challenge that services face when adults with mental health issues but who have mental capacity are very clear in their instructions that they do not want their personal information shared with their family. The mental health service handled this with great sensitivity, respecting ADULT D's wishes and feelings and in doing so they maintained ADULT D's trust. He remained in contact with the services over several years. However, it is also acknowledged that by not being in a position to inform the family about ADULT D's health and welfare, this has caused significant dilemmas and been distressing to ADULT D's family.

10.9 The SAR acknowledges that whilst an adult autism service has been developed in Milton Keynes, there was a gap in provision when ADULT D was diagnosed. He was not offered any counselling or other support that might have enabled him to come to terms with and understand the diagnosis. The experience of being on an acute mental health ward where other patients are experiencing critical mental health episodes can and is distressing and can impact on an individual with an ASC's well-being. It is therefore crucial that the lessons learned from this SAR are put into practice and appropriate protocols for supporting adults with high functioning autism are developed and this is prevented from occurring in the future. Good practice should be shared across the agencies. There were examples of effective multi-disciplinary working arrangement, joint home visits and timely intervention and mental health assessments and mental health act assessments.

11. Recommendations

11.1 All relevant staff in health and social care will be trained to understand the oppression and discrimination that is often experienced by adults with high functioning autism because this is a hidden disability that can be overlooked. This will be achieved through mandatory training and recorded in individual training records and through supervision records.

11.2 All relevant professionals from mental health services and adult social care working in the community with patients who are being discharged from hospital or have recently been discharged from the hospital must ensure they are fully aware of the patient's original reason for referral.

11.3 All relevant staff are trained to understand how the Autism Act 2009 gives the 'right to an assessment' under the Care Act 2014. Identified 'needs' may relate to accessing social support, welfare benefits, health care and employment. This will be achieved and measured through mandatory training, recorded in individual training records and through supervision records. This will also lead to better outcomes and a more personalised approach for adults with an autistic spectrum condition.

11.4 Joint protocol needs to be developed so that professionals are confident in recognising and managing the increased risk of suicide for people living with autistic spectrum conditions. Understanding risk markers for suicidality and how what has happened in the individual's past can impact on their future, particularly when there is a history of self-injury, unemployment and poor mental health. The protocol will improve communication between agencies and a co-ordinated approach.

11.5 MK Together Board should recognise that the lack of communication between DWP and health and adult social care and should develop links with DWP and other agencies who are not routinely involved in safeguarding arrangements and they should be included in relevant work and be part of the safeguarding arrangements in the future.

11.6 The Mental Health and Autism Social Care Team should always ensure that a home visit is made even if the person does not answer the door. A visiting card must be left and there must always be a double-check and a second follow-up visit arranged within a few days and

a manager must immediately be notified of the circumstances. Further inquiries should always be made and if the person has not been seen, then a referral to the Police for a welfare visit should be made.

11.7 Supported accommodation providers should ensure that any relevant information, especially relating to risk and safety factors, is passed to Social Landlords when moving their customers on to independent accommodation. This needs to be proportionate and provided with the consent of the service user.

11.8 A 'Dip sample' audit should be undertaken to check that the robust processes and protocols are in place as a result of this SAR and that they are being followed properly.

12 Glossary

ASTI	Assessment Short Term Intervention (team)
AHTT	Acute Home Treatment Team
AMHP	Approved Mental Health Professional
ASC	Adult Social Care
CCG	Clinical Commissioning Group
CPA	Care Programme Approach
CPN	Community Psychiatric Nurse
CMHT	Community Mental Health Team
CNWL	Central and North West London NHS Foundation Trust
DWP	Department for Work and Pensions
ERT	East Recovery Team
ESA	Employment Support Allowance
GP	General Practitioner
IAPT	Improving Access to Psychological Therapies
MCA	Mental Capacity Act 2005
MDT	Multi-Disciplinary Team
MHA	Mental Health Act 1983
SAB	Safeguarding Adults Board
SAR	Safeguarding Adults Review
TVP	Thames Valley Police
WCA	Work Capability Assessment

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