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INVESTIGATION

JANUARY 2016

Contents

| | |
|--|----|
| What we do | 1 |
| Introduction | 1 |
| Chair and members of investigation team | 2 |
| Method of investigation | 2 |
| About Ms MN | 3 |
| History of Ms MN's involvement with services | 4 |
| Ms MN's care in 2012 | 6 |
| January | 6 |
| February - March..... | 7 |
| April..... | 7 |
| The identification of the care home as a placement..... | 8 |
| May | 9 |
| June | 9 |
| July | 9 |
| August..... | 9 |
| September - October..... | 10 |
| November | 11 |
| Assessment of the suitability of the care home..... | 11 |
| The move to the care home | 13 |
| Handover to the care home..... | 14 |
| The care home care plans..... | 16 |
| Handover to the GP Practice..... | 17 |
| November – after the move to the care home | 18 |
| December | 19 |
| Day of Ms MN's death | 21 |
| Other issues..... | 23 |
| Adults with Incapacity (Scotland) Act 2000..... | 23 |
| Ms MN's diagnosis | 23 |
| Managing Ms MN's self harm and suicidal ideation | 24 |
| On the ward..... | 24 |
| In the care home | 26 |
| Choice of the care home | 26 |
| Prescription / medication | 27 |
| Staffing at the care home | 28 |
| Notification to the Mental Welfare Commission and subsequent investigations by the Board and the care home | 30 |
| Analysis | 33 |
| Recommendations | 42 |
| Appendix 1 – Glossary | 45 |
| Appendix 2 - Care Inspectorate inspection of the care home | 47 |

What we do

We protect and promote the human rights of people with mental health problems, learning disabilities, dementia and related conditions.

We do this by:

- Checking if individual care and treatment are lawful and in line with good practice.
- Empowering individuals and their carers through advice, guidance and information.
- Promoting best practice in applying mental health and incapacity law.
- Influencing legislation, policy and service development.

Introduction

This report is about Ms MN, a 44 year old woman with complex needs, who died after hanging herself in the care home to which she had recently been moved. We investigated the care and treatment which Ms MN received in the months leading to her death.

Terms of reference

This investigation was conducted under section 11 of the Mental Health (Care and Treatment) (Scotland) Act 2003. Section 11 gives the Commission the authority to carry out investigations and make related recommendations as it considers appropriate in a number of circumstances.

The terms of reference for our investigation were:

1. To examine all relevant healthcare, social work, and registered care setting documentation relating to Ms MN's care and treatment, with a particular focus on the period from January 2012 until her death in December 2012.
2. In particular, to review the transfer of Ms MN's care from Health Board A to the care home, primary care, and Health Board B, and to focus on the care plans in place and exchange of information to support her new placement.
3. To determine whether there was any deficiency in Ms MN's care and treatment during the period from the end of August 2012 until her death in December 2012.
4. To produce a report on the findings from the above, with recommendations for services, if appropriate.

Chair and members of investigation team

Dr Gary Morrison - Executive Director (Medical)
Douglas Seath - Nurse Officer
Tony Jevon - Social Work Officer

In addition this report was reviewed by Professor Stephen Lawrie who has a background in adult autistic spectrum disorder services.

Method of investigation

We obtained case records from Health Board A, the GP practice, the care home and Council A. We reviewed these records and also the investigations that had been conducted by the services following Ms MN's death. We then interviewed those we identified as key staff members.

The staff members we interviewed were:

- The consultant psychiatrist from Health Board A who was Ms MN's responsible medical officer (RMO)
- Ms MN's social worker
- The senior charge nurse from the ward
- The manager of the care home
- The director of operations at the care home
- Three nursing staff at the hospital
- Three staff at the care home

We contacted Ms MN's family but they did not wish to take part in the investigation.

We met these individuals privately and considered beforehand the questions that we wanted them to address. We arranged to have these interviews recorded and a transcript of each was sent to the relevant interviewee to check for accuracy.

About Ms MN

Ms MN was 44 at the time of her death. She was born and brought up in Area A, and had one sibling. She lived at home with her parents until her early 20s. At the time of her death, she had had no direct contact with her family for many years.

She had a range of complex needs and behavioural issues. Early records show that she slept poorly, drank tea obsessively and had other compulsive behaviours such as drying herself after a bath until she had abrasions on her skin. She was described as a loner and was bullied at school. She could have aggressive outbursts and assaulted family members and others on occasion. She left school at the age of 16 with no qualifications and never worked.

Ms MN was socially isolated and was unable to manage her personal affairs. For some years she lived alone in a local authority flat. Her flat became uninhabitable due to neglect of her personal hygiene. She drank alcohol regularly and smoked heavily. She hoarded things. When living at home she was supported mostly by the Area A community outreach team (COT) who described her as living in squalor.

Ms MN often came into conflict with the police, either because of disputes with neighbours and misuse of alcohol, or because she was the victim of crime. She told people she did not feel low temperatures, and frequently dressed inappropriately for cold weather, sometimes being found barefoot in winter, and requiring treatment for hypothermia.

She was diagnosed with Asperger Syndrome, and did not have a learning disability, a point that becomes important in this investigation. She could not cope with changes to her routines. For instance, she had to have her own tea cup, and to have tea and cigarettes, and 'as required' medication, at the times she wanted them, otherwise she became distressed and agitated. Any change in routine or in her environment could cause her to become agitated.

History of Ms MN's involvement with services

Ms MN had a history of contact with mental health services which started in 1986 at the age of 18, when she was reported to have a four year history of anxiety, panic attacks and obsessional thoughts and rituals.

In 1988 she was admitted to hospital for six weeks and diagnosed with asthenic personality disorder (now more commonly known as dependent personality disorder). The first record of her taking an overdose is in 1989. In 1995, she was assessed as developing a psychotic illness.

Ms MN was admitted to hospital for four months in 1998 following an episode of suicidal ideation. It was noted that she had very poor self care, with obsessional thoughts and rituals, and psychotic symptoms. A possible diagnosis of schizophrenia was made. She was discharged to homeless accommodation and referred to the learning disability service because of possible Asperger Syndrome. In 1999, she was assessed by a psychologist and diagnosed with autistic spectrum disorder. Even minor changes in her environment caused her distress.

Ms MN's responsible medical officer (RMO) at the time of her death was a consultant psychiatrist in Health Board A who had worked with her for many years. He told us that the main difficulties "were to do with her Autism/Asperger Syndrome" and the diagnosis of schizophrenia was only an issue for a couple of months. He described the difficulties of "maintaining scrutiny of her mental state and her engagement with mental health services, and reviewing and trying to maintain her safety in the community".

Between 2000 and 2011 Ms MN was admitted on multiple occasions every year for detoxification following harmful misuse of alcohol, severe self neglect, suicidal thoughts and aggression towards others. She was noted to be vulnerable to physical and financial abuse; she was robbed and assaulted in her own home twice during 2010. She had 25 admissions during 2010 and 2011. Community support services, including autism specialist agencies, were unable to engage with Ms MN. She was referred to the regional autism service in 2009 for a specialist review but the team could not access her. Following this failed attempt, there were no further attempts to obtain a specialist assessment.

Latterly, the community outreach team reported that she would not allow them in to her flat to see her, or to clear rubbish, and that they felt at times they were checking whether she was still alive. Ms MN would be admitted to the acute ward when things became too difficult for her at home. She would discharge herself when she felt more settled.

The community outreach staff involved in Ms MN's care had grave concerns about her safety and wellbeing, and found working with her very challenging. They described her living conditions as being squalid and unsafe. She had been robbed in her own home because she never locked the door.

The consultant psychiatrist explained that Ms MN had frequent respite admissions to the acute admissions ward (the ward), and they increased over the two years prior to her being detained. Ms MN was placed on the care programme approach (CPA), and team members from different agencies met to look at various options. We were told that Ms MN was very clear in her mind that she wanted to retain her independent living in the community, and that she chose to live her life in the way that she did.

Ms MN's social worker and mental health officer (MHO) told us that the plan had been for her to be considered for a rehabilitation service rather than an acute admission mental health ward, because she found the hospital environment really difficult, but this had not worked out and she was admitted to the ward.

In August 2011, Ms MN was placed on a hospital based compulsory treatment order (CTO) which remained in place until her death.

Note

The account of the last year of Ms MN's life which follows details the 'as required' medication given to Ms MN in the months before discharge from the ward. The reason for this detail is that her medication was very important in the management of her care. Ms MN strongly influenced the type and frequency of medication she was given. It was very important to her, and was a source of friction between herself and medical staff if she did not get what she said she needed, when she asked for it.

Ms MN's care in 2012

January

Ms MN was an inpatient in hospital A, a psychiatric ward in Health Board A. In early 2012, a care plan was established whereby Ms MN was permitted to leave under suspension of detention and return to the ward as she wished. Medication was stopped when she was in the community because of the risk of overdosing. These periods sometimes lasted a week or more, and she was supported by the community outreach team (COT). Ward staff agreed to contact the COT every fourth day if she had not returned from time off the ward. The COT recorded that the door to her flat was often found open when she was out. The flat was in disarray and unhygienic. They would visit to try and encourage her to clean her flat, do her laundry and take her medication, but if she was in she would not open the door. The nurses would communicate with her through the door, but often they could not get into her flat to see or help her.

When Ms MN was back living at home, there were numerous incidents of severe self-neglect, self-harm, intoxication and breaches of the peace that involved police intervention. Suspension of detention was stopped because Ms MN was assessed as being a severe fire risk in her flat.

When on the ward, Ms MN had frequent episodes of agitated and aggressive behaviour towards staff and other patients. She was on occasion physically restrained and sedated.

Episodes of aggression highlighted that Ms MN's mood could change very quickly. It was sometimes difficult for trained nursing staff to manage. If calming techniques and reassurance failed, nursing staff would sometimes have to call for assistance from a doctor. On such occasions they often used 'as required' medication.

The medical file records clear evidence that nursing staff sat and talked at length with Ms MN about her fears and feelings. One entry recorded that she did not want the proposed move to supported accommodation in another area, because she was concerned that if she needed admission to hospital at any time, nursing staff on the new ward would not know her.

In January, she had 76 individual doses of 'as required' medication (not including her regular doses of zopiclone which is a non-benzodiazepine used in the treatment of insomnia) including 22 intramuscular injections of midazolam (a short-acting benzodiazepine used for rapid tranquilisation).

February - March

On several occasions in February and March it was noted that Ms MN was angry at being kept in hospital due to the poor weather. She sometimes left the ward without authorisation and police had to be called to return her. Restraint was used to return her to her room.

On these occasions nurses noted she was distressed, agitated and intoxicated, and in a poor state of personal hygiene. She told nurses she had been unable to sleep when at home, could not cope without her zopiclone and blamed the consultant psychiatrist for making her institutionalised. A multi-disciplinary team meeting recorded the consultant psychiatrist's view that Ms MN had been "on a downward spiral for the past two-three years and her ability to function [was] declining". The COT noted their "visits [were] not planned and at times [had] been just to check that [Ms MN] [was] still alive".

It is clear that the multi-disciplinary team were concerned for her welfare and the associated risks of allowing her to have time off the ward. They considered her "care plan [was] the least restrictive option to prevent a requirement for staff intervention and sedation and a move to a higher level of security". If Ms MN did not return from pass, then the COT was instructed not to take any further medication out to her. The plan was agreed that ward staff would contact the COT every fourth day when she was out on suspension of detention.

April

In April, there were numerous incidents of severe self-neglect, self-harm, intoxication and breaches of the peace that involved police intervention.

On the 1st April 2012, police notified the ward staff that Ms MN had been seen by neighbours outside in the street, in a state of disarray. Ms MN said that she had drunk bleach the night before, so an ambulance was called to attend. The police returned Ms MN to the ward ten minutes later. A doctor advised that she go to A&E for blood tests and assessment. She attended A&E but refused medical intervention. A&E staff sent her away without any tests completed. The COT then visited Ms MN's house – the door was open, and they noted the flat was in a dirty, unhygienic and potentially dangerous condition.

Ms MN was allowed on suspension of detention again, and a few days later she returned to the ward feeling suicidal and smelling of alcohol. She requested 'as required' medication to take home. The nurse sought advice from the consultant psychiatrist, and 'as required' medication was not given. Ms MN left the ward an hour after returning. The care plan noted that "[Ms MN] to be placed on pass if not returning from current pass". "No medication to be issued for passes due to risk of overdosing and drinking alcohol". "The consultant psychiatrist advised that any judgement would have to be made on the basis of how [Ms MN] [was] on return to

the ward, and that it would be up to staff to judge if she [was] to remain on the ward or be placed back out on pass again". Later the same day, police brought her back to the ward. Her notes referred to the state of her personal hygiene, which was poor, and stated that "after lots of persuasion she had a shower." "She may as well be dead, she states". The COT was asked by ward staff to pick up Ms MN's cigarettes from her flat. The door was open, and the flat was as previously described. They found cigarettes half-burnt on the floor beside empty bottles of vodka. Suspension of detention was stopped because Ms MN was assessed as being a severe fire risk in her flat. From this time, Ms MN was only allowed escorted time outside the hospital.

The consultant psychiatrist wrote to the general manager of Health Board A mental health service at this time, asking for community rehabilitation resources to help support the care plan for Ms MN. The general manager wrote back to say Ms MN was not a suitable candidate for the rehabilitation service, but may benefit from some of the resources that they planned to develop in future. He added "the onus on funding, and funding appropriate supports for this lady, does lie with the social work at the moment".

The identification of the care home as a placement

In May, Ms MN's social worker identified a possible placement for her at a care home located within Health Board B (the care home). The publicity for the unit described it as a purpose-built advanced specialist care home, designed to facilitate the special needs of individuals with a learning disability and other mental health complications. Staff from the care home described it as dealing with associated behaviours that may challenge staff. The social worker was confident that she had the right information at the time she made the referral, and that there was nothing to suggest that the care home would not have managed Ms MN. The social worker had seen the care home's brochure, spoken to staff and visited the care home, and felt there was every chance they would be able to provide care for Ms MN.

The consultant psychiatrist told us that his view was that Ms MN's best hope was for the health and social care team to find somewhere for her to live where she could be enabled to control her environment as much as possible, and minimise change. He thought that this would lead to a reduction of stress, and a reduction in the need for her to use suicide as a coping strategy. This had been their hope when she was discharged to the care home.

The manager of the care home told us that Ms MN was unusual in that the other people who lived in the unit had a primary diagnosis of learning disability, whereas for Ms MN it would have been her mental health that was their primary concern.

May

At the beginning of May, 'as required' lorazepam was briefly discontinued. Quetiapine, an atypical antipsychotic, approved for the treatment of schizophrenia, was begun. The ward review meeting noted that "if behaviour escalates, de-escalation, medication, and seclusion are to be employed. If to no effect, intensive psychiatric care unit (IPCU) to be considered".

Ms MN told nursing staff that she would have to be watched 24 hours a day when she was transferred elsewhere, as she would hurt herself.

In May, her medication consisted of methotrimeprazine up to 25mgs three times a day and as required – six doses, quetiapine – as required 11 doses, lorazepam as required – 40 doses (more than a daily dose), zopiclone - as required 30 doses (equivalent to a daily dose), midazolam IM as required – two doses.

June

In June 2012, Ms MN 'stormed' off the ward, and restraint was used to return her from hospital grounds. She stated to nurses that she did not want to go to the care home, as she would not be allowed alcohol and it would be like she was "under section for the rest of her life". She said that she couldn't bear this, and she tried to tie her jogging trousers to the shower head in her bathroom and hang herself. The duty doctor was contacted to authorise 'as required' medication.

The following week Ms MN asked to speak to a nurse about the care home and raised anxieties about the restrictions she would face. Later she attempted to abscond and 'safe and therapeutic Interventions' (SATs) were used. The duty doctor was called and agreed to 'as required' medication.

July

In July 2012, Ms MN absconded from the ward. The missing person procedure was implemented and police returned Ms MN, who was inebriated. A council housing officer came to the ward to report that her flat was infested and locks had been changed. He said that Ms MN would lose housing benefit soon, and asked if she intended to return to the tenancy. He was told by nurses that this was very unlikely.

August

In August 2012, Ms MN was struggling with being in hospital, and described it as feeling she was in prison. She continued to express unwillingness to go to the care home. Nurses recorded that Ms MN had again tried to hang herself, in her shower room, with pyjama bottoms.

During July and August Ms MN remained unsettled, but she was given plenty of opportunity to discuss her anxiety, and nursing staff tried to support her. She was still only allowed off the ward with a nurse escort, and she occasionally took the

opportunity to abscond. On one occasion she was returned to the ward, inebriated and shouting, by three police officers. A nurse recorded that Ms MN “spoke of her concern about the move to [care home] and worried that the consultant psychiatrist will keep her there until the day she dies.”

At the end of the month, Ms MN visited the care home and seemed more relaxed, as her bedroom would be near a kitchen, and near an exit where she would be able to smoke. However, the following day, she told staff that she hated the place. She continued to express this view in September, saying that the residents there had learning disabilities and she was more intelligent than them. She said she was concerned she would end up ‘going berserk’ and staff would be unable to manage.

In August she was given ‘as required’ medication: zopiclone, 26 doses, midazolam IM, one dose, methotrimeprazine, 22 doses, and lorazepam, 58 doses.

September - October

Throughout September 2012 and October 2012, and until she was transferred in November 2012, the pattern repeated itself. There were several episodes of aggressive behaviour towards nursing staff, expressions of suicidal ideation, and repeated fears of the impending move. The response was the same, SAT interventions and ‘as required’ medication were used until she was calm, and the duty doctor was called to see her.

In October, Ms MN told staff she wanted to die, and again tied pyjama bottoms to her shower to attempt to hang herself. She was given ‘as required’ medication, but did not think this was helping. On the 25th October, the ward charge nurse, the consultant psychiatrist, and the social worker met with staff from the care home to give up-to-date practical information about how nursing staff deal with Ms MN during periods of distress.

At the end of October Ms MN absconded and threatened to burn nurses with a lighter. Police returned Ms MN to the ward inebriated. The nurse recorded she “spoke about not wanting to go to the new place in [town], said she would hate it and give the staff a really bad time so that she would get sent back to the ward”. The duty doctor was contacted.

Ms MN’s ‘as required’ medication in September was: chlordiazepoxide, 47 doses, lorazepam (1/9 - 4/9), 11 doses, and zopiclone, 30 doses.

In October, her ‘as required’ medication was: zopiclone, 30 doses, methotrimeprazine, two doses, chlordiazepoxide 43 doses, and lorazepam, 35 doses. A junior doctor noted that she had been taking her full prescribed amount of ‘as required’ lorazepam, and therefore he increased the prescribed amount.

November

On the 6th November 2012, two days before her transfer to the care home, nurses recorded that Ms MN “had reported to staff that she had again attempted to hang herself with her jogging bottoms from the shower rail. Later she tried to abscond from the ward again. When she was stopped from leaving she “attempted to burn herself with a cigarette lighter”. Restraint had to be used and she assaulted a nurse. The duty doctor and hospital security were called out. This was the fourth occasion Ms MN had said she had attempted to use her jogging bottoms to hang herself.

Assessment of the suitability of the care home

The care home manager told us that the planning for admission took several months. She said that primarily she did not do the assessment, but that it was done by her line manager, the director of operations. However, he told us that it was the care home manager’s responsibility to assess MN’s suitability for the unit, and Ms MN was admitted to the unit on the basis of her assessment.

Two assessments by care home staff were done during June. The care home manager did one visit, and support worker A and support worker B (from the care home), visited the ward on a second occasion. A ward nurse recorded that the care home manager felt from her initial meeting with Ms MN that placement in the care home would be appropriate.

The care home manager told us that she thought some of her staff had worked in the ward alongside the nurses. She believed a nurse at the care home, and a key worker, spent ‘a bit of time’ with Ms MN in the ward. Ms MN “wasn’t great at interaction and it was a real short stay, but I think by the end they were staying an hour to two hours, kind of building it up so she got to know them”.

The senior charge nurse (SCN) from the ward told us nursing staff from the ward were given an information leaflet and they met the care home manager. They were not so sure how appropriate a placement it was in terms of its learning disability role. However, from the way that the manager spoke about it, that Ms MN would have her own room, would have her own access to tea and coffee, and a garden, so she wouldn’t have to mix with the other residents, they were happy for Ms MN to go there. Other than on the day she transferred on suspension of detention, none of the nursing staff had visited the care home, and the SCN did not see this as their role.

The SCN was certain that when they met the care home manager, they talked about Ms MN’s risk of suicide and mentioned her trousers as being used by Ms MN as a possible ligature. She also tried to describe how they would support Ms MN when she made comments about harming herself. The SCN did not know how they could have passed on to the care home staff their experience of years of working with Ms MN. She told us they had meetings, phone calls, and provided documentation such

as risk assessments. She believed they had been very thorough in trying to pass over as much information as they possibly could. The SCN and the consultant psychiatrist also had a discussion with the care home manager about the medication they were using.

During the care home's investigation in February 2014, support worker B, said that she had thought Ms MN was not suitable for their service. However, the report she wrote at the time went missing, and has not been located. Support worker B said the discussions they had with ward staff about Ms MN's behaviour and Asperger Syndrome were not "very in-depth, as the staff were busy on shift". Support worker A, who accompanied support worker B, reported that there had not been much discussion about Ms MN's care plan, or about how hospital staff would continue to support her. He said he was told, regarding 'as required' medication that Ms MN was to get it when she wanted it, because no one knew her like she knew herself. He reported he was not made aware of any incidents of suicidal intent by hospital staff on this visit, not even of self harm, just low mood. He thought Ms MN's main diagnosis was more mental health than Asperger Syndrome or learning disability. The care home manager told us she could not remember whether there were any concerns expressed by staff about the care home being the appropriate place for Ms MN.

Support worker A told us that the visit to the ward was less of an assessment and more like information gathering, or an introduction. He and support worker B spoke to Ms MN for about 20 minutes. He gave her a brochure about the care home. She asked them if she could smoke in the unit, and they told her there was a smoking area and offered other information about the unit.

The community psychiatric nurse (CPN) from the COT told us that she thought it seemed that the care home would cater for Ms MN's needs. At the one meeting that the CPN was involved in, she highlighted all the issues that the COT had experienced to the care home manager. She remembers sharing the risk assessment and other relevant details, and the manager seemed to think they would be able to manage Ms MN's challenging behaviour.

The consultant psychiatrist told us that when he met the staff from the care home, he went over the risks, including the risk of suicide, with them. However, he could not remember if the exact method Ms MN had used in the ward on several occasions (and which she finally used in the care home), had been discussed with them. He acknowledged that she had a life-time risk of suicide and that her best hope of reducing that risk was to have found a way of living where she could do what she wanted to do, in an environment that was controlled, that was free of excess stimulation, and that she could cope with. He believed Ms MN's challenging behaviours, self-harm and episodes of aggression were triggered by an

overwhelming anxiety that she experienced; usually related to something in her environment that had distressed her.

The director of operations at the care home (the director of operations), told us very plainly that they would have been absolutely clear with referrers when they admitted Ms MN that they were not equipped to care for people who were suicidal. His understanding was that “her self-harm was about self-harm and not necessarily trying to commit suicide, and that’s the way I remember it being described to us by referrers when we met her...We had refused admissions before on that basis, because we didn’t have that level of expertise, and the environment wasn’t right”. He told us that ‘quite a few’ of the residents at the centre self-harmed, and that this was managed through risk assessments, and risk management plans. The director of operations told us that if they had known that Ms MN had attempted to hang herself with her trousers four times in her last period of admission to the hospital, they would not have admitted her.

A letter sent to the Council A social worker confirmed that following assessment on 12th June 2012, Ms MN had been offered a placement at the care home. The care home charged £2,200 per week. Ms MN contributed £96.35 of her benefits per week towards the cost.

The move to the care home

Nursing staff from the ward told us that Ms MN was given plenty of time to come to terms with the idea of the move to the care home, and although it wasn’t her choice, nursing staff did give her time to discuss her thoughts and fears. They thought that Ms MN came to a point where she was accepting that it would be her next step. The consultant psychiatrist kept the bed on the ward open for her, as there was always a chance in his view that she wouldn’t manage the transition.

The consultant psychiatrist told us that normally they would have trialled things out in this situation; offering day passes and then overnight stays to the person being transferred. But in this case he said they decided that this would be counter-productive because it would result in an increase in anxiety. They considered the best thing to do was just to go for it and see what happened.

Immediately before discharge, nursing staff felt Ms MN appeared mentally much better. The episodes of being verbally aggressive had been reduced, and Ms MN thanked nursing staff for the care they had provided. Although she didn’t want to go to the unit initially, one nurse remembers that Ms MN would talk about her feeling that maybe it would help her, but then again, her view would fluctuate.

Ms MN was transferred to the care home on 8th November 2012. Records show that “staff [in the care home] were informed of her specified person status and the reason why. Informed of need for regular access to tea-making facilities...Informed staff at

[care home] of the ward telephone number if they need to ask for advice...Ms MN advised them of her displeasure about ready access to tea making facilities which she had been promised. On return, the consultant psychiatrist advised that compulsory treatment order (CTO) had been suspended”.

One of the nurses from the ward accompanied Ms MN. He told us that he tried to do a handover to the staff there, but they said they already knew all they needed to from the reports.

Handover to the care home

The care home manager remembered that the care plans were completed by the time Ms MN moved to the unit. They were planned along with NHS staff and at multi-disciplinary team meetings in the ward. The care home manager said there were several support plans for different aspects of her behaviour. She noted that Ms MN was heavily dependent on her ‘as required’ medication, and that there was a support plan in place for that. They also had a support plan on her chart regarding her challenging behaviour, but the care home manager didn’t know if there was anything on Ms MN’s risk of suicide. She told us “I don’t know if that had ever been a risk that was highlighted”. She mentioned that there wasn’t any support from the ward once Ms MN had moved. The support all happened in the transition to the service.

The care home had a report on a file written by the social worker in March 2012 which clearly recorded that Ms MN had a diagnosis of schizophrenia, Asperger Syndrome and alcohol abuse. It highlighted her severe self-neglect, thoughts of self-harm and high levels of anxiety. It noted Ms MN “needs support to maintain all aspects of any living environment”. It listed her risks as:

- Self-neglect including poor nutrition, hypothermia and squalid living conditions.
- Exploitation by others – poor home security has led to intruders who have exploited her financially, physically and sexually.
- To others: when [Ms MN] becomes anxious and is unable to manage a situation, she can be physically and verbally aggressive to anyone around her.
- Alcohol misuse: Linked to risk of choking on vomit, injury and not seeking medical intervention, consequences for memory and cognition, unsafe smoking.
- Self-harm and suicide. Ms MN has overdosed on medication in the past
- Non-engagement with proposed care plan.

The social worker also provided a thorough single shared assessment, a risk management plan and copies of care programme approach (CPA) documentation.

The care home was further provided with a joint Health Board A / Council A "Working with Risk" form. The "summary of assessment" was that Ms MN had attempted suicide and self-harm in the past, was physically and verbally aggressive towards staff and patients, had a long history of alcohol abuse, neglected personal care and that her compliance with medication was poor.

The care home also had a copy of a psychiatric summary written by the consultant psychiatrist in March 2009. Given the intensive experiences of healthcare staff caring for Ms MN over the past 12 months as a continuous in-patient, a more detailed, up-to-date report on her presentation and her management through 'as required' medication might have been more useful. Nevertheless, the assessment of the risks Ms MN posed remained relevant:

"Ms MN represents significant risk to herself and others. There have been numerous reported attempts at self-harm including overdose, ingestion of bleach and attempted hanging. She has been exploited financially and sexually and bullied by others because of her inability to secure her property. She has assaulted staff and other patients on a number of occasions as well as family members. She regularly threatens to go to a high place in order to throw herself off, to run in front of a car or to electrocute herself with a domestic appliance. The conditions in which she lives are best described as absolute squalor, but she often refuses to have anything done about this. Her drinking is heavy and harmful and there is increasing evidence that she is developing liver damage".

A discharge prescription was given to the care home staff, but there was no record of them being told about the complexities around this. There is no record of staff being given details of her recent suicide attempts and the method most often employed.

There was no written care plan agreed with Health Board A about how care home staff should respond if Ms MN repeatedly asked for as required medication, although there was a general verbal offer that care home staff could phone the ward regarding any aspect of her care. The senior charge nurse told us that as far as she remembers, care home staff phoned the ward for advice on a couple of occasions after Ms MN was discharged, and they were more than willing to give this. The calls had been about changing her 'as required' medication. Nursing staff had said to the care home that they (the nursing staff) had a lot of knowledge, so if the care home was struggling with anything, they should feel free to phone them. Nursing staff believed they made that very clear. When the staff nurse involved in the move came back from transferring Ms MN, he said he had asked if there was anything else that the care home staff felt ward staff needed to tell them. Care home staff said "no, there's enough paperwork here, we have loads of information". The staff nurse had reiterated they could phone if they needed anything.

When asked about the discharge plan, the consultant psychiatrist said he had kept Ms MN under care programme approach (CPA) arrangements. He planned to attend the four week review and he told us the social worker had been to visit the care home on a couple of occasions. The consultant psychiatrist had made a referral to the psychiatric team in the care home's area. He told us he deliberately hadn't planned to visit the care home in the first few weeks because he thought Ms MN might respond badly to his visiting. He believed the discharge arrangements "were quite tight and quite well organised in the sense that we felt we had found a solution that was going to work for [Ms MN] and that we had managed the transition in a way that caused her the least uncertainty and anxiety."

The care home care plans

A crisis intervention support plan (CRISP) was initiated when Ms MN moved to the care home. It referred to a range of approaches to provide guidelines for staff to anticipate and defuse potentially challenging and violent situations. The guidelines identified that the trigger points that may make Ms MN agitated could be:

- Not being understood by the person she is talking to.
- Talking to people in authority.
- Being told there is a change in her routine.
- Being made to sit in a room with other service users.
- Being told that she cannot have something i.e. a cup of tea or a cigarette.

It does not mention friction over being refused medication. It highlighted that she may express violence in the form of shouting or throwing things, suicidal thoughts or attempting to harm herself.

"A consistent approach is required from all members of staff during these times in order to provide a familiarity with [Ms MN's] routine. If this routine is changed, challenging behaviour may occur".

The CRISP plan guides staff through a range of options to support Ms MN at these times, such as speaking calmly, offering tea or a cigarette, moving her to a quiet area and, if necessary, if challenging behaviour occurs, using minimal physical restraint and moving her to her bedroom. It does not mention 'as required' medication, or whether observation should be maintained, and it does not mention how to reduce the risk of self harm or suicide at these times. It does not mention seeking advice from the ward staff or consulting her responsible medical officer (RMO).

There were also a range of "holistic assessment and support plans" (HASP) completed regarding support needs such as housing support, mobility, recreation, physical health, continence, night care, and personal hygiene.

There is evidence in the care home's notes that staff worked well with Ms MN regarding some of these areas. For instance, they managed to get her to agree to night staff taking her clothes and washing them overnight and returning them in the morning. Previously she had become very agitated if staff told her to change her clothes.

In respect of self harm, the care plan was to engage Ms MN in conversation to find out how she was feeling, to offer alternatives to self harm such as pinning an elastic band which seemed to reduce her anxiety, and offering her 'as required' medication "to help her cope with anxiety".

There was a HASP for medication – "to reduce anxiety levels, to keep healthy as possible". Unfortunately most of the sheets recording Ms MN's medication for the period she was in the care home are missing. When we raised this with the managers of the care home they tried to locate them, but were unable to do this. Other file records from the care home were also missing.

The director of operations told us they had a good relationship and robust arrangements for general support from the learning disability psychiatry team in Health Board B. However, the learning disability psychiatry team had refused to take over the care of Ms MN because she did not have a diagnosis of learning disability, and there was no input from the mental health service to the unit. The director of operations said that it was the responsibility of the referrer, or the RMO, to identify and arrange hospital follow up in Health Board B. They made it "absolutely crystal clear, whether it was psychological or psychiatric, we had none of those services available, and that was never ever under any doubt". He said that it was often the case that the individual was admitted before their care had been handed over to the local consultant, but the staff in the unit did not involve themselves in this transfer of healthcare responsibility.

When Ms MN moved on suspension of detention to the care home it should have still been services in Health Board A that were meant to be providing follow up care.

Handover to the GP Practice

A fax was sent by the consultant psychiatrist to the local GP practice on the 23rd November 2012, two weeks after Ms MN's transfer. It contained a report written by him (addressed to the social worker) to assist Ms MN's funding application (that application was dated 14th August 2012), and a copy of a referral letter to a consultant psychiatrist in Health Board B (dated 5th November 2012). In the fax he apologised to the GP practice for the poor communication and wrote that a full discharge letter would follow.

A junior doctor, who worked with the consultant psychiatrist, wrote a discharge summary report and sent it to the GP practice. It eventually arrived nearly a month after Ms MN had died.

It noted Ms MN's medication on discharge (8th November 2012) as:

| | | |
|-------------------|---------|--|
| Diazepam | 5mgs | three times daily |
| Diazepam | 10mgs | nightly |
| Lorazepam | 2mgs | 1 hourly as required up to 4mgs in 24 hours |
| Zopiclone | 7.5mgs | nightly |
| Methotrimeprazine | 25mgs | three times daily |
| Methotrimeprazine | 25mgs | as required, 8 hourly to a max of 50mg in 24 hours |
| Chlorpheniramine | 4mgs | 4 to 6 hourly as required, max 24 mgs 24 hours |
| Melatonin | 4mgs | once at 6pm |
| Pregabalin | 150mg | nightly |
| Pregabalin | 300mg | at 1pm |
| Trazodone | 150mgs | nightly |
| Omeprazole | 20mgs | at 1pm |
| Salbutamol | 2 puffs | as required |
| Procyclidine | 5mgs | 8 hourly as required, max 15mgs in 24 hours |

Paracetamol, E45, and Senna

In the consultant psychiatrist's letter to the consultant psychiatrist in Health Board B, Ms MN's diagnosis was given as "firstly schizophrenia and secondly Asperger's Syndrome". In the discharge summary by the junior psychiatrist (CT1), as well as the Immediate Discharge and Prescription Form from the ward, and Ms MN's T3 form, Ms MN's diagnosis was given as Asperger Syndrome and alcohol dependency.

Although the GP practice had several contacts with the care home during the period of Ms MN's stay, they recorded in the notes after police informed them of her death, that Ms MN "had not yet been seen by anyone at the practice".

One problem was that Health Board A staff would have liked to have registered her with a GP, and passed on discharge information to that GP before she was transferred, but she could not be registered until after she had moved. They also could not identify who the RMO was going to be in Health Board B, because they couldn't register her with a GP. The consultant psychiatrist believed a major problem with the discharge care planning had been that they could not pass on information about Ms MN's complex needs to the GP until after she had moved.

November – after the move to the care home

Ms MN was sometimes unsettled and verbally abusive to begin with at the care home. It was recorded by staff that she was "upset, did not want to stay in [the care home]". On one occasion she lifted a cup and threw it, hitting another resident. On

another she punched a support worker on the chest and threatened to kill her. Ms MN could be very agitated throughout the day and demand 'as required' medication. Support worker A recalls from the few shifts he worked with her that it was difficult to engage her, as she would spend most of her time in her room coming out just for cigarettes and tea. He remembered that her 'as required' medication was to be given as and when she requested it, and that she was assessed as suitable for using the kitchen. She was not allowed access to a lighter, but the majority of the staff smoked at the time, so she could get a light whenever she wanted.

A staff nurse, at the care home contacted the GP practice on 20th November 2012 to request all of Ms MN's medication on a repeat prescription, and requested from the GP practice the addition of haloperidol (used to relieve the symptoms of schizophrenia) 2mg 'as required' medication. The nurse explained that Ms MN had requested haloperidol as she used to get it when in hospital on the ward, and it meant she used less lorazepam. The GP practice recorded they "had no instructions from the hospital and that Ms MN is on quite a few other drugs – unsure if you would like to stop some of those?" The GP practice sent a fax back to the care home noting one of the GPs had had a discussion with the consultant psychiatrist, and noting that Ms MN "has had five mgs of haloperidol up to twice daily in hospital. Could therefore have 1.5mg tabs, 3 up to twice daily (equivalent of 4.5mg)".

On the 23rd November 2012, staff informed Ms MN that she would not be prescribed more haloperidol that day. They recorded that she did not respond well to this and became more agitated. She said she "wanted to die" and that she "doesn't like it here" and mentioned the only reason she hadn't hurt herself was because she "couldn't find anything to hurt herself with". She attempted to assault the nurse who had tried to speak to her. She threw items around the room. Staff requested haloperidol (at Ms MN's instigation) from the GP, who refused to prescribe it. Ms MN was restrained by two staff. In her room, she sprayed deodorant in her eyes. These were bathed before she was escorted to hospital due to the inflammation and redness being severe.

December

In December, a typical daily record showed that Ms MN asked for 'as required' medication regularly and was given lorazepam 2mg and procyclidine 5mg [although this had not recently been prescribed and is not normally given for agitation]. But she would remain in "a heightened state of anxiety," and requested more 'as required' medication. She continued to say that she hated being there, and she felt she had been "dumped" and only been out once since she got there".

Procyclidine is usually used to counter the unwanted side-effects caused by some medicines. We are not sure why Ms MN was given procyclidine for agitation, and we have been unable to speak to any of the nursing staff who worked in the care home during this period. It appears in one note that Ms MN may have requested

procyclidine herself. A handwritten sheet given to the GP Practice on the 19th November entitled “medication requested by [the care home]”, lists the medication prescribed to Ms MN and the diagnostic reason. Against “procyclidine 5mg as required” it gives Asperger Syndrome as the reason it was prescribed (this is true too for methotrimeprazine). The consultant psychiatrist told us he had not been aware that the care home had been giving Ms MN ‘as required’ Procyclidine for agitation. On 4th December 2012, it was noted that Ms MN had fresh scarring on her arms. Staff removed a broken CD from her possession with her agreement. The next day Ms MN told staff that she had been drinking shower gel, which she claimed contained alcohol. At her request, staff contacted her social worker regarding access to alcohol and were informed that, due to past misuse, it would not be permitted.

In the HASP for medication, it records that ‘as required’ medication was given virtually every day. A typical entry was “12/11/12 [Ms MN] asked for her ‘when required’ procyclidine and lorazepam for agitation. Given 2mg lorazepam and 5mg procyclidine at 14.45 to good effect”. Or 16th December 2012 Ms MN “requested PRN medication twice today for anxiety and panic attacks”. The next and last entry in this HASP was “[Ms Ms MN] refused to see eye optician when offered”. Some HASP records have gone missing. The care home management are aware of this.

One of the support workers from the unit told us that, on the 16th December 2012, Ms MN “spoke with support staff and was expressing suicidal ideas saying she had thought about hanging herself in her wardrobe but didn’t go through with it”. She asked for her ‘as required’ medication twice for anxiety and panic attacks. She remained agitated.

When Ms MN displayed distressed behaviour, if there was someone who had managed to build a rapport with her in the past, then they would go and try to speak to her first. If that didn’t work, then different people would try different ways of speaking to her until someone ‘got through’. If her behaviour escalated to the point of becoming unmanageable, Ms MN would be asked to go to her room, where staff would try to speak to her away from everyone else. If it became a violent situation, they would stay with her until they could speak to her calmly and she acted in a calm manner.

If Ms MN wanted her ‘as required’ medication she would tell the support staff, and tell them specifically which one it was that she wanted. Sometimes the nursing staff would agree with her, though they would try and talk to her first, with the aim of her no longer needing it.

One of the support workers from the care home (support worker 1) said Ms MN didn’t talk about how she would commit suicide – she just said that she wanted to do it. The support worker had heard that Ms MN had attempted to commit suicide

before, but said that the support workers didn't really get told about it in detail, and they didn't have any training on it to tell them what to do if the situation arose. Another support worker (Support Worker 2) told us that she was unaware of Ms MN's previous suicide attempts. Support Worker 1 told us she would just try and reassure Ms MN, let her know that everything was okay, and that she was safe. She would then pass the information onto the nurse in charge for her or him to document it.

Support Worker 1 told us that staff did not take Ms MN's threats seriously. She told us of one occasion when a staff nurse came on night duty when she was finishing her shift, he said "that's her starting again, "I want to die, I want to die, give me a cup of tea" and basically he just laughed it off. I said "that was so inappropriate and went and grabbed my bag and left".

The last time Support Worker 1 saw Ms MN she wasn't any different. The support worker recalls the whole time Ms MN was in the unit she was "low in mood, depressed, just very sad all the time, so she wasn't any different nearer the time that she done it".

On a positive note , the support worker told us that now, if any residents "even so much as hint" at having suicidal ideas they are put straight onto raised observation levels, and given one-to-one support for however long is necessary, "but back then, she would talk about it daily, and it just went right over everyone's head".

Day of Ms MN's death

Records indicate that the day of her death began as usual. There was a new support worker on shift, supernumerary to the shift, and an experienced agency registered mental health nurse (RMN) who had worked on the unit on six previous occasions. Support workers and domestic staff noted Ms MN's heightened levels of anxiety, and informed the RMN at lunchtime that Ms MN was talking about suicide.

Having given Ms MN 2mg of lorazepam 'as required' medication in the morning, the nurse rang the GP practice at 1.45pm. She had just given her 2mg more, and wanted to find out if she could give her another 2mg above her prescription. Ms MN was still agitated and the nurse was sure she would demand more later. The GP (who had never met Ms MN) suggested the nurse "sticking to her guns", "she can have two more now but would get no more later. Due meeting to which original psychiatrist is invited. Suggest staff bring this up at the time". There was due to be a "four-week review" with the consultant psychiatrist in Health Board A the next day. It was being held nearly 7 weeks after discharge.

The care home say there was evidence that the RMN and support staff had spent time with Ms MN throughout the day, facilitating cigarette breaks, making tea, and

supporting her to contact her solicitor so that she could challenge her compulsory treatment order.

There was a short period of time during which Ms MN went to her bedroom. When this was noticed, the new member of staff went along to see if she needed support, and found her hanging from a rail in her wardrobe. She had used her trouser leg as a ligature. Resuscitation attempts began immediately and emergency services reached the unit within 15 minutes, but Ms MN could not be revived and she was pronounced dead at approximately 17.45pm.

Other issues

Adults with Incapacity (Scotland) Act 2000

Welfare guardianship under the Adults with Incapacity (Scotland) Act 2000 could have provided a legal framework at the times Ms MN was not in hospital, for the community team to, for instance, gain access to Ms MN's flat, ensure that her flat was clean and habitable, and work with her regarding issues of personal safety, health and nutrition. However two doctors would have had to have certified that she lacked capacity to make these decisions herself, in order for a guardianship application to be made.

The consultant psychiatrist told us he felt that she had capacity to make decisions and he stood by that view. He told us he referred Ms MN to the regional autism service in about 2009 for a specialist review but the specialist who tried to visit her wasn't able to access Ms MN. He tried to visit on a few occasions and then she indicated to the team that she wasn't prepared to take part in the assessment. Although he hadn't seen her, the specialist "raised doubts about her capacity", but the consultant psychiatrist was clear in his mind that she did have capacity, although the decisions she made were "quite ill-judged". He told us he "didn't think guardianship would be very effective anyway because it didn't offer powers of compulsion".

Section 70 of the AWI Act actually does allow for those seeking guardianship to apply for enforcement powers. Where any decision of a guardian with powers relating to the personal welfare of the adult is not complied with by the adult (or by any other person), then a sheriff may, on an application by the guardian: "make an order ordaining that the adult or any person named in the order to implement the decision of the guardian", and, "where the non-compliance relates to a decision of the guardian as to the place of residence of the adult", the sheriff may "grant a warrant authorising a constable to enter any premises where the adult is, or is reasonably supposed to be, to apprehend the adult, and to remove him to such place as the guardian may direct."

This power has been used to enforce a care plan on adults who lack capacity and who do not want to comply with the decisions of their guardian, such as not wanting to allow support workers into their flat, or refusing to accept guidance on personal hygiene, cleanliness, and where they live.

Ms MN's diagnosis

Ms MN was being treated by the acute adult mental health service in Health Board A and had had a diagnosis of schizophrenia. The consultant psychiatrist explained that, as an older teenager, she had had a psychotic episode. At that time it was appropriate for her to be treated by adult mental health services. There was one

period during the time that he knew her where she had presented with psychotic symptoms and that was in about 2008. Over the course of two months she had expressed persecutory ideas and hallucinations, and responded very well to anti-psychotic medication. Her symptoms had resolved and he told us she didn't wish to take anti-psychotic medication over the longer term.

We asked the consultant psychiatrist about her presentation with suicidal ideation and self-harm, and whether she had a diagnosis of depression. He told us Ms MN had a great deal of anxiety, and at times he felt she had low mood, but at other times he thought she did not. He did not think her suicidality was in the context of low mood. He thought there was an issue that her life was of pretty poor quality. He thought her suicidality and self harm were in the context of stress and not secondary to a depressive episode.

The SCN told us that Ms MN had a very challenging presentation for ward staff, mostly because of her Asperger's diagnosis, but they very rarely saw any symptoms of mental illness.

Throughout the records we have examined, her diagnoses are variably given as personality disorder, schizophrenia, Asperger syndrome, or a combination of these.

Managing Ms MN's self harm and suicidal ideation

On the ward

Ms MN mentioned and attempted self-harm or suicide on a number of occasions while she was on the ward. We asked the consultant psychiatrist how her risk of suicide had been assessed. He told us it was something that she did when she was anxious. He thought it had been a more persistent presentation when he first knew her. He would assess whether her being in hospital was increasing the risk, rather than reducing the risk of suicide, and consider discharging her. He assessed that her suicidal attempts were "maladaptive coping mechanisms in response to stress".

When he first knew Ms MN he told us there were "lots of incidents of going to high places, putting herself in traffic, taking substances and so forth" which, rather than being part of a treatable mental condition, he considered to be her maladaptive coping strategy. He was worried that by reinforcing this behaviour the health team's interventions were increasing her long term risk of suicide.

The consultant psychiatrist told us that anything that involved change was distressing to Ms MN. The healthcare team had great difficulty managing this in an acute psychiatric ward setting, because changes happen all the time, and anything that involved her not being able to manage her environment would lead to her becoming distressed.

Over the years of managing Ms MN's care and treatment as an in-patient, the consultant psychiatrist told us he had evolved a strategy of "just getting her off the ward" when she became distressed. He said that, for the most part, over the last year when she was subject to compulsory measures, if she was expressing distress then he would put her 'on pass'. Previously, before she was subject to compulsory measures, he would have discharged her. Eventually those working with Ms MN came to the decision that it wasn't sustainable for her to be living independently in the community. He told us there were a couple of occasions, possibly three, where she nearly died because of hypothermia. Ms MN apparently didn't feel cold. She never dressed appropriately for the weather. She only ever wore a tee-shirt and track suit bottoms. She couldn't see that because she didn't feel cold it didn't mean that she didn't get cold, and that she needed to protect herself in cold weather. So, he told us, if the weather was cold then he would have to keep her in the ward and there were significant challenges managing her behaviour associated with that. If it was summer time then he would let her go home.

The SCN told us that they couldn't have a set care plan that fixed what they would do with Ms MN. The staff had to be flexible and adapt minute by minute, especially when she was upset and distressed. She described how staff had learnt to de-escalate situations – "one day you could talk to her and another day it would have to be medication". Talking to her for one hour and then another hour would not help; it would have to be medication. "You really had to just keep thinking on your feet all the time with her and that was from the very first time I knew her, right through". Sometimes the nurses had to remove whatever was upsetting Ms MN, or remove her to another place where they could reduce the stimulation. Her view was that an acute admission ward was the "totally wrong environment" for Ms MN.

The ward staff set down rules for Ms MN, for instance that she had to bathe at least once every three days, and Ms MN was aware of this and kept to the rules. Ward staff told us they worked hard to build up trust with her and eventually she got to know their routine. Ward staff (check) mentioned that on the day she was discharged, Ms MN came up to the nurses to thank them for everything they had done for her; she showed how much she had really appreciated it. Ward staff told us that staff had built up knowledge of how to manage Ms MN through time, patience and experience.

We asked about how the nursing team managed Ms MN's suicidal ideation. The SCN said that ever since she had first started working with Ms MN, Ms MN would say that she was going to kill herself. She would voice her ideas of self-harm in the same tone as she would say "I want a cup of coffee".

When Ms MN said something like this ward staff would, for a period of time, look to make sure she was safe. The SCN told us Ms MN couldn't cope with being on

constant observation. In the SCN's view, it was too invasive for her, although there were times when she was put onto constant observations over the years. So if she went to her room, nurses would follow her and then ask her "Is there any medication that I can get to help you, let's make the bed", just so that they were actually with her for that period, and eventually Ms MN would change the subject and ask, for instance, what time is tea.

In the care home

We asked the care home manager about the care home's procedure for when a resident expressed suicidal ideas. The care home manager said that, at the time, they hadn't anything in place for increasing observation. She said a change came about following the incident with Ms MN and that observation policies have been put in place as one of the lessons learnt.

She recalled Ms MN had "a little bit of history about threatening to take her own life, but there were no actual real concerns about risk". She thought the issues for Ms MN had been about a bridge, or a road near her house, and she would get drunk and run onto the road. When Ms MN came to the unit they didn't think that this would be a risk, as the residents can't get to a road and there is no bridge. The care home manager did not know what kind of approach they would have taken if Ms MN had threatened suicide.

The care home manager could not recall any concerns being expressed about suicidal ideation once Ms MN moved to the care home. The concerns were about whether she wanted to be in the care home. The manager said Ms MN would be quite content and going about her normal business, and then she wouldn't want to be there and she wanted to phone her social worker.

Choice of the care home

The consultant psychiatrist told us Ms MN had an IQ in the normal range, and that even though the acute psychiatric ward was not ideal for Ms MN, the learning disability service would not take people who have IQs above the learning disability range. There was no in-patient setting within Health Board A where she could have been more appropriately managed.

Key to their plan for Ms MN was to identify a suitable care home for her. The consultant psychiatrist told us that there were very few options for them to consider. The placements he knew of within Health Board A would have faced the same problems as the ward. He had considered that a rehabilitation service might be suitable for her, but she had expressed a view that she did not want this, and after discussion he agreed with her. The rehabilitation service would not have the option that the acute ward had of allowing her home for a few days if things got too much for her, and there was a risk that she would have ended up in the intensive

psychiatric care unit (PCU) if her behaviour deteriorated. There was no specialist care home for people with autism in Health Board A, and no 24-hour supported accommodation that would have been suitable for her. Ideally he was looking for a low stimulus environment where there were people around who could ensure that she was properly nourished, and warm in winter, and who would also be able to limit her access to alcohol. He reminded us Ms MN didn't deal with uncertainty, and if anything happened that wasn't part of her routine, she would react explosively to it. He had not been able to find any strategies that de-escalated this.

He thought that when the social worker identified the care home it sounded ideal. It claimed to have expertise in dealing with autism, and he told us the care home wanted to move into the provision of care for adults with IQ in the normal range. He thought it sounded much more promising than anything else that was around.

Prescription / medication

We asked the consultant psychiatrist about the complex prescription of different 'as required' medications over the months prior to Ms MN's discharge. He told us it was "very hit or miss" whether her 'as required' medication worked or not. He told us there was no question she sometimes would have peaks in anxiety, and that anxiolytic medication might have helped that a bit. He explained that over the years he tried various strategies, including longer term anxiolytic medication. Sometimes it appeared that it was helping, and things would get better, and then there would be a situation where Ms MN felt out of control, or something happened, and she became over-whelmed by her anxiety. 'As required' medication was part of their strategy in trying to deal with a difficult situation where he did not believe there were very many effective tools.

Immediately before her transfer to the care home we identified from looking at all the prescription sheets that Ms MN's 'as required' medication was still changing on a very regular basis. It appeared to us that Ms MN would often ask for more medication, or a change in her medication from one drug to another, and very often it seemed the changes she requested were given to her. We asked the consultant psychiatrist what care planning had been put in place to cope with this aspect of her treatment after discharge.

He told us they had arranged to hold a review four weeks after discharge, but that she had died before they managed to have that review. (Ms MN died after 41 days in the care home and the review was to have been the following day – six weeks after discharge). He accepted that usage of 'as required' medication was led by Ms MN. "There wasn't a strategy for PRN medication. I took a view that if [Ms MN] felt that something helped, then we would use that, and if [Ms MN] felt it didn't help then we would use something else. So in that sense no, there wouldn't have been a consistent strategy for PRN medication because [Ms MN] herself would have a lot experience and different views about what she wanted".

We asked the SCN about the use of medication to manage Ms MN. She clarified that Ms MN's medication was for distress and not mental illness. She remembered they had changed Ms MN onto a regular medication shortly before discharge, and were reducing the amount of 'as required' medication they were giving her. They had consulted with an old age psychiatrist about medication for agitation and he had made a recommendation. Ms MN was the only person that she knew that had used this medication, and the SCN felt it had "taken the edge off" the level of distress expressed by Ms MN. They still had to use 'as required' medication with her. Ms MN would tell them herself when she needed this or that medication and staff "had to have the keys in your hand to get into the treatment room to unlock the medication, or else she was elevated again. She would be more distressed. That's how quick you had to respond to [Ms MN's] levels of distress".

The care home manager told us that if anyone took regular 'as required' medication they would ask the GP to review it, and he would come and prescribe the medication. She thought staff were working on a plan to do this. She said there was one tablet in particular that Ms MN counted on, and planned her day around. She thought Ms MN had been on the same medication for years, and it was known that she would abuse her 'as required' medication. She would tell one nurse she hadn't had it if a different nurse was on shift, so the nurses had to be very vigilant when giving her 'as required' medication.

Staffing at the care home

The director of operations told us there had been an issue with recruitment and retention of nurses with the right clinical experience, knowledge, and background for the types of individuals that were being supported. His assessment was that the organisation needed to be more competitive in their terms and conditions, and that was beginning to happen, but during this period they were finding it difficult to hold on to nurses with the right qualifications.

It was a similar story for support workers – he told us it was difficult because staff would face the risk every day of being assaulted, punched or slapped and so the job wasn't for everybody and sometimes it took a while to establish a stable team. They tried to recruit as best they could and in terms of support workers he felt they had a core of settled and experienced staff, but he acknowledged there was definitely a significant turnover.

He recalled that the service had mainly employed permanent nursing staff, although on the day Ms MN died, it was an agency nurse on duty and she had worked on the unit five or six times before that day.

They tried to block book so that they only used a couple of nurses over a month if they knew they were going to be struggling. Despite this plan he told us there was no doubt that having to use agency staff made it difficult to provide the service they

had hoped to, and he remembered that one of the learning outcomes from Ms MN's death was about developing a bank and trying to stick with one agency and trying to get the agency nurses in for all the on-site training in policies and procedures. Agency nurses were not just turning up at a standard residential service where they could probably get through without specialist induction. He noted that at the care home anything could happen "and often did".

The director of operations acknowledged that "when you care for people with such complex needs it takes time for people to get to understand the communication systems that are in place", so that when there is a turnover of staff it "absolutely" has an impact. He recalled that the care home had a "fairly robust" induction process, but there was no doubt for someone who is on the autism spectrum, change of staff and routines can affect their behaviour, and they worked to minimise that.

We asked if they would have told referrers about the staffing difficulties they were having. The director of operations told us that that is not something he would have said, but they would not have accepted referrals if they had not been staffed sufficiently.

The care home manager told us that staff turnover in the unit was high when Ms MN was admitted. She believed the high staff turnover would have had an impact on the consistency of approach. However, she believed Ms MN's key worker and named nurse remained the same throughout her stay, but the unit staff certainly did change, and this included management changes too. She said when they opened the unit, they took on quite a few nurses who were newly qualified, but they gained a bit of experience and went on to jobs in the NHS. She added that when Ms MN was there, the support workers were on the minimum wage and were often working really complex cases. This has changed since.

Support Worker 1 told us that at that time Ms MN was in the unit, they didn't have very many nurses. So the nurses "were kind of up to their eyes in paperwork". She found this stressful because they were running on about two staff a shift in Ms MN's unit, a nurse and a support worker, but she told us she didn't really think about it much then because she hadn't been in the job long. She said they weren't able to spend any time with the residents. They weren't able to do anything with them, "no activities or anything like that".

The two support workers who we interviewed as part of this investigation had previously worked in shops and bars; one had done some voluntary experience in a care home. Support Worker 1 told us that when she first started she didn't get an induction or any training. She "got thrown into working on the floor basically. They were really short staffed at the time". She got training by shadowing another member of staff. She could not remember any training specifically about working with the kind of people that were on the unit.

Notification to the Mental Welfare Commission and subsequent investigations by the Board and the care home

In compliance with the Mental Welfare Commission's (the Commission) notification requirement that it be informed of the death of individuals detained under the Mental Health (Care and Treatment) (Scotland) Act 2003 (the Act), the consultant psychiatrist wrote to inform us that his patient, Ms MN, had died in December 2012 in an apparent act of suicide. He mentioned her death was the subject of a police investigation and a report was being compiled for the Procurator Fiscal.

On the 8th January 2013, the Commission received an initial report by a clinical services manager (mental health) in Health Board A. The report concluded that although Health Board A had continuing care and responsibility relating to Ms MN, given that she died in a neighbouring health board, in a registered care home setting, and nearly six weeks after discharge, they did not intend to conduct a separate review of the event. She said she understood that the Care Inspectorate would be taking the lead role in the incident review and indeed, that they had already launched their own inquiry, in which she said Health Board A would be fully involved.

We checked with the Care Inspectorate that this was accurate and they told us that there must have been a misunderstanding as they had no plans to carry out an investigation in to the death of Ms MN. We reverted to Health Board A and asked them to coordinate with Council A to hold a joint critical incident review with the care home. The general manager at the time agreed to do this, although he was concerned that it would have limited scope, as Health Board A had no jurisdiction to consider the practices of the care home.

On the 27th February 2013, Health Board A held an internal clinical review. A copy of this review was sent to the Commission on the 7th June 2013.

Neither the social worker from Council A nor the manager of the care home attended the review. The Health Board A review group concluded that Health Board A staff who had been involved in Ms MN's care described being shocked and surprised by the manner of her death. It noted that although she always voiced some suicidal ideas, it was never felt to be the primary risk factor for her. They identified she was very impulsive and neglectful of her own well-being and unable to keep herself safe, and in their view, that was felt to present a much greater risk to her than suicide.

Health Board A staff who had worked closely with Ms MN, some for many years, had described feeling guilty that they were not there to support her at the time of her death, but recognised that the situation, in which they had been supporting her as an in-patient prior to her transfer to the care home, was not sustainable in the long term.

They recognised that they did not have a lot of information about Ms MN's time at the care home as staff from the care home were unable to attend the review. The review group reached the conclusion that her death could not have been predicted.

In view of their non-attendance at the Health Board A review, on the 10th June 2013, the Commission wrote to the care home manager requesting they now hold a critical incident review, or provide a copy of one if this had already been carried out. It was not until the 15th October 2013 before they sent a copy of a "summary review".

Their summary review concluded that Ms MN had frequently presented with suicidal ideation or thoughts of self harm during her six week stay, and had been given additional staff support and 'as required' medication to help her cope with these stressful thoughts. She had on occasion carried out an act of deliberate self harm. On the last day of her life she had, as usual, on a number of times throughout the day, spoken about hurting or killing herself. The RMN on duty had, as before, discussed with a local GP giving her "as required" medication. Later, as she had already taken her daily limit, further 'as required' medication was refused her. Ms MN took an opportunity to leave the shared area of the care home to return to her room. She used a pair of trousers to form a noose and suspended herself in her wardrobe.

The care home review concluded with several learning points. A training need was identified. The review identified that the RMN on duty was from an agency and had limited knowledge of the care home's policies and procedures. Their staff rotation system needed to be reviewed to ensure that all staff had experience, and were knowledgeable about the residents. It noted that ancillary staff were often closest to the residents, and needed wider training as part of the overall team. One support worker on duty admitted he had not read the care plans, and he agreed to undergo further training. It identified that new staff needed more robust induction, and there needed to be better management of the level of disturbance in the unit to ensure a better environment in which to provide care.

The Commission wanted to know more detail of the care plan for Ms MN. She was still subject to a compulsory treatment order and her responsible medical officer was still the consultant psychiatrist in Health Board A. On the 15th October 2013 we wrote to the care home asking what involvement there had been between their staff and the consultant psychiatrist in the six weeks prior to her death. We asked whether there had been any discussion, and an agreed care plan, about the dispensing of 'as required' medication. We wanted to know how well the GP who had been consulted knew Ms MN.

We discovered that there were no written care plans agreed with Health Board A about 'as required' medication. The consultant psychiatrist had not had any contact with the care home since Ms MN's transfer on suspension of detention, and they had

no record of contacting him or the nursing staff in Health Board A about her episodes of agitation when refused 'as required' medication, or her suicidal and self harming presentation. None of the GPs in the local practice had ever seen Ms MN.

It was at this time that the Commission decided that there were sufficient concerns and issues relevant to other people being cared for in the community in specialist care services, to initiate an investigation.

We asked why no one from the care home had attended the Health Board A led critical incident review. The care home manager at the time of the incident told us it would have been normal practice to attend, but the letter had been addressed to the care home director of operations, who had been on "garden leave" at the time, and it wasn't until after the review had been held that the letter was passed to her.

Analysis

Assessment of Asperger Syndrome

There was never any specialist assessment of Ms MN's Asperger Syndrome. The consultant psychiatrist had attempted to obtain this when Ms MN was living in the community, and Ms MN had refused to engage with the assessment. This is not a surprise. It was well recorded that she did not always get on well with doctors, and found it easier to relate to more junior staff. She found it difficult to interact with people she did not know, she did not like meetings, and she often found it difficult to keep appointments. These may all have been attributes of her Asperger Syndrome, or her personality.

Even within the general context of people with autistic spectrum disorders, Ms MN's needs were particularly complex and challenging. The best and most specialist care possible may have struggled to respond to her difficulties and afford her a reasonable quality of life. But it is precisely because her needs were so unusual and difficult that we believe further attempts at specialist assessment would have been justified. Even if this could not have been arranged while Ms MN remained in the community, her period of in-patient detention under the Mental Health Act would have afforded the opportunity to undertake this assessment.

Assessment of capacity

Ms MN's care was influenced by a clear view of the consultant psychiatrist that she had capacity in the context of the Adults with Incapacity Act. On that basis interventions such as welfare guardianship were not an option (he felt these would be unlikely to succeed in any event), and she was able to make choices about her personal and medical care, including refusing specialist assessment. The exceptions to this were interventions covered by the Mental Health (Care and Treatment) (Scotland) Act 2003, namely detention and treatment for mental disorder. We are not in a position to judge whether the consultant psychiatrist's view of her capacity was correct. However, in the context of autistic spectrum disorders, it is important to be clear that the absence of an identified learning disability, or a psychotic delusional state, is not conclusive. The test of incapacity at s1(6) of the Adults with Incapacity Act could be met where a person's disability means their ability to cope with a decision making process is severely compromised. In this case, the community outreach team described a shockingly clear level of deprivation, lack of self-care, and an inability to change her lifestyle to improve her quality of life. More generally, Ms MN's behaviour over a long period suggests someone whose responses were driven largely by an inability to cope with choices; an inability that was essentially a consequence of her disability.

It is also notable that the psychiatrist and a mental health tribunal were satisfied that she met the criteria for detention under the Mental Health Act. One of the necessary

grounds for this is 'significant impairment of decision-making ability'. This is not the same test as incapacity, but the Code of Practice¹ makes clear that it addresses similar issues.

We believe that a specialist assessment of Ms MN's capacity to make decisions about her treatment and personal welfare should have been undertaken.

Responsibility for care

Ms MN had a range of identified needs and depending on whom we spoke to one or other of these needs appeared to be the major component of her presentation. The medical staff based in the hospital thought Asperger Syndrome was her principal diagnosis. The care home staff believed she presented more with mental health problems. When she was referred on to Health Board B, initially the referral had been sent by her RMO to the learning disability consultant psychiatrist, but when this referral was rejected he re-directed the referral to the mental health consultant psychiatrist in Health Board B.

Two issues arise from this. The most robust and consistent diagnosis appears to be Asperger Syndrome. As we comment below, we believe people with this diagnosis too often fall between mental health and learning disability services, or are pushed into one or other category, when their needs are distinct.

However, even presupposing there were more specialist services for individuals diagnosed with autistic spectrum disorder, there will be occasions when they are cared for by mental health or learning disability services. When someone's needs are as complex as Ms MN, it is vital that there is clarity about the responsibility for care, and the chain of communication.

When Ms MN transferred to the new care home no health board consultant psychiatrist had accepted responsibility for her care, and there was no instruction for staff in the unit, or the local GP practice to refer all complex decisions regarding her medication and treatment directly to her RMO, the consultant psychiatrist in Health Board A.

¹ [Chapter 1, paragraph 22 of Volume 2 of the Code of Practice for the Mental Health \(Care and Treatment\) \(Scotland\) Act 2003](#) which says

"The concept [of significant impairment of decision-making ability] is separate to that of incapacity as defined under the Adults with Incapacity (Scotland) Act 2000. However, when assessing a person's decision-making ability, it is likely that similar factors will be considered to those taken into account when assessing incapacity. Such factors could involve consideration of the extent to which the person's mental disorder might adversely affect their ability to believe, understand and retain information concerning their care and treatment, to make decisions based on that information, and to communicate those decisions to others."

In this case, the local learning disability clinical team had rightly identified that Ms MN did not have a learning disability. The local mental health team had not agreed to take on responsibility for her care.

Formally, the RMO retained a role while Ms MN remained subject to the Mental Health Act, and care programme approach arrangements were in place, but these were not reflected in the way that the discharge was planned and communicated to the GP service.

This left the local GP practice struggling to manage her medication, treatment and care, having never met Ms MN and having only minimal information about the complexities of her care.

GPs provide general medical services for individuals with a wide range of conditions. However, it should not be assumed that they can provide the specialist input and treatments required for residents with complex needs in care homes. This can often only be provided by doctors with the necessary skills and clinical expertise.

Handling discharge

We accept that attempts were made to pass over information to the care home so that they were aware of, and able to cope with, Ms MN's complex needs. We also accept that an approach involving trial visits could well have been counter-productive if it increased her anxiety.

However, our interviewees disagreed in many respects on how much the home was aware of important matters including previous suicide attempts. We do not believe that the care home understood the full range of Ms MN's needs, particularly in relation to responding to demands for medication and self-harming behaviour or threats. More should have been done to ensure that Ms MN's needs, and the approach which the hospital had taken to accommodating her behaviour, were fully communicated to the home, and an appropriate strategy to respond to this was agreed amongst all concerned.

From the contact we can see between the care home and the GP Practice, it is clear that the careful consideration and planning that would have been essential to ensure good communication and handover by the medical team from Hospital A was not in place. Once the medication that Ms MN was given by the hospital to take away with her had run out, the care home staff had to struggle to obtain repeat prescriptions and had to pass on information themselves to the GPs.

Although Ms MN was now living in the community, she was still on a hospital-based compulsory treatment order, and her responsible medical officer was still the consultant psychiatrist. This should have led to a clear chain of communication between the home and the RMO.

Overall, we conclude that there were significant clinical failures in the planning and execution of the transfer to the care home.

Was specialist care being provided?

One reason that a specialist clinical assessment may not have been obtained, even after Ms MN was detained in hospital and it would have been easy to arrange, was that shortly after her admission a specialist care home provider was identified. The care home advertised itself as providing advanced, specialist care, for people with a learning disability and behaviours that challenged services. A senior manager from the service visited and assessed that Ms MN would be a suitable referral and felt her needs would be met within his service. The unit where Ms MN was going had only recently opened, although the provider had been operating a similar service for a year or two in another unit on the same site.

Because of the specialist service it claimed to offer, the new unit was more expensive than usually agreed to from a local authority budget, and a joint health and social care funding application needed to be made. None of the individuals who identified the care home had previous experience of using it, and no detailed check was made that it was able to deliver the specialist service it advertised.

The social worker did do a visit to the unit and it appeared to her to be a modern, clean, new, purpose-built unit set in a secluded rural location. They had in place facilities such as tea and coffee making that would have been important to Ms MN and they seemed to be working with people who had similar needs. As such it seemed to be ideal.

The consultant psychiatrist felt it was likely the unit would fail to manage Ms MN, but believed it was the best available option, and better than continued admission in the acute mental health ward, or discharge back to her own tenancy.

However, in reality, the new unit was struggling to find staff with the essential skills, they were often reliant on agency nurses who had little or no experience of autistic spectrum disorder or Asperger Syndrome, and they were stretched coping with another resident who demanded a lot of staff time. The local manager had been given responsibility for the new unit in addition to her already busy role. For many of the frontline support workers, it was their first experience of work in a care setting of any kind, and their induction was mostly by shadowing.

We do not believe the service was justified in claiming to offer a specialist service appropriate for Ms MN's needs at this time. We also conclude that Health Board A did not do enough to assure itself of the suitability of the placement. Notwithstanding the lack of any obvious alternative, there should have been a more thorough examination of the ability of this service to meet Ms MN's needs.

Training in ASD

One of the problems facing Ms MN was that, as well as the absence of specialist assessment, none of the medical, or nursing staff we spoke to who worked with her had any significant training in the needs of people with autistic spectrum disorders. This was true even after she moved to the specialist care unit.

Management of risk of suicide

Even had the care provider been better established with experienced staff, they would have struggled to manage Ms MN. Her care plan was complex. She presented many demands on a service that needed a responsive and well trained staff group familiar with her needs.

The consultant psychiatrist did not think Ms MN presented as a high risk of suicide. When she said she wanted to kill herself, this was, in his opinion, an expression of distress and not an intention to die. For this reason there were no risk assessments completed to guide care staff regarding suicidal ideation. The care staff we interviewed could not recall being told about her regular threats to kill herself, and none were aware that in the months prior to her transfer to the unit she had attempted suicide on four occasions, using exactly the same method that she eventually used in the care home.

In our view, there was a known and high risk that Ms MN would attempt to harm herself and, whether intentionally or otherwise, end her life. The response to this should have been clearly identified and agreed.

Managing medication

During her last admission to the hospital ward, Ms MN frequently demanded her medication be changed, and often increased. If this did not happen almost immediately, it is well recorded that her behaviour would become challenging, and she would threaten self-harm or become aggressive to others. When she was discharged on suspension of detention her medication was still in flux, changing on a regular basis. Junior doctors were routinely being called to the ward to discuss and authorise changes in her medication.

Meetings between healthcare staff and staff from the new unit were not frequent, and although both remember them taking place, any decisions made were not clearly recorded.

A list of Ms MN's current medication was given to the new unit with supply for a number of weeks. Staff in the new unit were aware that she may demand additional 'as required' medication, but there was little thought given as to how this might be agreed or altered and authorised. The consultant psychiatrist thought they might ring the ward as he continued to be the responsible medical officer, but this was not

clearly written down, and staff in the new unit thought they should communicate with the local GP practice.

In this situation, it was inevitable that Ms MN would struggle when she felt she needed more medication, and her anxiety would have been considerable when she discovered, as in fact she predicted, that staff did not know how to respond to her in these circumstances.

In particular, it appears to be the case that Ms MN was effectively in control of her medication while she was in hospital. The clinical team had concluded that it was generally best to let her decide when she needed medication and what she needed. This is a highly unusual situation in relation to a detained patient. It may have been justified, but it is not surprising that difficulties were caused in a new environment where this expectation was not understood by all those responsible for decisions about medication, including the GP practice.

The consultant psychiatrist was not at all sure the placement would last long, and he kept a bed open for her return to the ward should it fail as he expected. He also found that Ms MN could not be registered with her new GP practice until after she moved into the new unit and had a local address.

As a result of the confusion, faxes had to be sent with apologies for poor communication, transfer letters arrived too late, and GPs who had never met Ms MN were being expected to make decisions about her complex medication regime based on minimal knowledge or understanding of her complex needs.

Investigation of the incident

When the Commission first heard about the death of Ms MN, we were told that Health Board A did not feel it was their responsibility to carry out a critical incident review. The general manager told us that as the death took place in a registered care setting, he thought that the Care Inspectorate were taking responsibility for the review. He thought Health Board A would have had a limited role.

When the Commission discovered this was a misunderstanding, there was still some reluctance from Health Board A to lead on a review because the health board would have no authority over what happened in the care setting. If the Commission had not followed this up, there would have been no review into the circumstances of the death of Ms MN.

When a review did proceed, it took place without any representative from the care home because the letter had been sent to a manager who was on "garden leave". The care home should certainly have had some procedure in place to open the manager's mail, but a telephone call from the health team would have established what the situation was quickly.

The Health Board A review focussed on Ms MN's care in hospital and was very positive about the standard of care she had been provided in hospital. It did not identify any learning. The review barely mentioned that she was still on suspension of detention at the time of her death, did not mention any of the several similar attempts she had made on her life in the preceding months, and did not link the disorganised transfer of her follow up medical care over to Health Board B, and the GPs, as a possible factor in her death. It mentioned how sad it was that Ms MN had taken her own life at precisely the time when she had been given this opportunity to a new life in the care home, although it did not mention the RMO thought the transfer would fail.

Suicide may indicate a service failure in a registered care setting in the same way that any other serious incident may. HSE carried out an investigation and interviewed the RMO and the social worker. Notably, the social worker stated to them that she believed care home staff were trained in Aspergers and would be able to manage Ms MN because they had other residents with similar needs.

The HSE findings from their initial investigation were that:

“In the case of [Ms MN] there was no diagnosis of risk from suicide, there was no risk assessment to identify controls as she was not considered to be at risk, and in the past she had been permitted to go for respite visits to her own home when the hospital environment resulted in continual challenging behaviours”.

The wider policy context

Autism can be a serious, lifelong and disabling condition that affects the way a person communicates with, and relates to, other people and how they experience the world around them. Some people with this diagnosis can manage with very little or no support, many need a wide range of supports to live their life, and a few can only manage with 24 hour care. In Scotland specialist autism services are not widely available, although the situation is improving, with a few providers offering a limited range of services in each area, but with few services on offer specifically for adults with autism within the NHS.

Although mental health problems are more common among people with autism and it is estimated² that one in three adults with a learning disability also have autism, many people diagnosed with autism do not have either a learning disability³ or any other mental health diagnosis, and they fall into a wholly unacceptable gap between

² Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey, The NHS Health and Social Care Information Centre (2012) <http://www.hscic.gov.uk/article/1733/New-study-estimates-autism-prevalence-among-adults-with-learning-disability>

³ 23.3% of adults on the autism spectrum known to local authorities were reported as not having a learning disability. SCLD “Learning Disability Statistics Scotland, 2014” <http://www.sclld.org.uk/wp-content/uploads/2015/08/Learning-Disability-Statistics-Scotland-2014-report.pdf>

two services inappropriate for their needs. Ms MN, struggled to access any specialist autism healthcare services, leaving mental health or learning disability services to manage as best they could.

In 2011 the Scottish Government announced the Scottish Strategy for Autism, a national ten year autism strategy to put focus on the implementation by health boards and local authorities of existing legislation and duties. At the launch the Minister for Public Health announced that the Scottish Government would provide £13.4 million over four years, to support implementation of the strategy. None of this funding was used specifically in Health Board A and most was aimed at children and young adults in education, or in transition to adult services. In a second injection of funding announced in June 2012, Health Board A – Child Psychology Department, received £5,000 to provide a group based intervention programme for parents of children who have recently received a diagnosis.

We recognise that there is a threat that by developing specialist services for one condition other conditions may end up neglected. There is also a threat in expecting general adult psychiatry and learning disability services to obtain lengthy specialist assessments for people with autistic spectrum disorders which would be associated with other opportunity costs. There needs to be a balance therefore between adequately resourcing specialist services and facilitating general services to increase their skills and experience in this as in other areas.

The Scottish Autism Strategy has clear aspirations to improve the range of services for people on the autistic spectrum, raise awareness of the issues for individuals, their families and carers, and encourage staff training in autism. It is also highly desirable that there is an increase in the skills and experience of mental health and other staff in diagnosing and managing people with autistic spectrum disorders. The implementation of the Scottish Autism Strategy appears to have been piecemeal across Scotland, with areas of excellence and others where it has had less impact. Professor Jean MacLellan, Chair, of the National Autism Co-Ordination Project, noted in November 2014 that “the landscape is varied currently with regard to local strategy plans”⁴. In December 2015 Professor MacLellan promoted the need for local authorities to focus on access to integrated service provision across a person’s lifespan and the importance of building the capacity and awareness of mainstream services to ensure that people are met with recognition and understanding of autism.⁵

We recognise both the commitment of the Government and the wide range of work which is underway under the auspices of the Autism Strategy. As the strategy makes clear, it will take years before we can be satisfied that all people with autistic

⁴ [Scottish Autism Strategy, Governance Group meeting minutes 11th November 2014](#)

⁵ <http://www.autismnetworkscotland.org.uk/scottish-strategy-for-autism-fourth-annual-conference>

spectrum disorders are receiving appropriate support across the lifespan, using holistic and personalised approaches.

In the meantime, though, we cannot accept that people with autistic spectrum disorder and complex needs should expect to be fitted into services designed for very different client groups, with a tacit acknowledgment that, while people are doing what they can, it is unlikely to succeed.

Ms MN undoubtedly challenged services, and many people did their best, within limited resources, to help her. Even with the best support imaginable, she would have faced many difficulties. But there are many groups who in the past who were felt to be beyond effective intervention – whether people with learning disabilities who were deemed ‘ineducable’ or the ‘incurably insane’. There is no easy and quick solution, but we cannot accept that people with autistic spectrum disorder and complex needs should expect to be fitted into services designed for very different client groups, with a tacit acknowledgment that, while people are doing what they can, it is unlikely to succeed. No-one is beyond help, and Ms MN’s tragic death has lessons which we need to heed.

Recommendations

Specialist assessments

For joint health and social care bodies

1. Where behaviours related to Asperger Syndrome and other autistic spectrum disorders are a significant factor in a person's presentation, and the clinical lead or responsible medical officer has not had training in autistic spectrum disorders, a specialist assessment should be obtained to aid management and care planning.

For psychiatrists and social workers

2. Where an adult with Asperger Syndrome or other autistic spectrum disorder is behaving in a way which puts themselves at serious risk, and this behaviour is felt to be attributable to the condition, a specialist assessment of capacity and decision making ability should be undertaken to inform possible interventions under the Mental Health (Care and Treatment) (Scotland) Act 2003, the Adults with Incapacity (Scotland) Act 2000, or the Adult Support and Protection (Scotland) Act 2007.

Commissioning specialist services

For the local health board

3. Health Board A should review its commissioning procedures to ensure it can be satisfied that, when commissioning a specialist service from a third sector or independent sector provider, the agency is able to deliver a service which is appropriate for the needs of the service user(s), including having appropriately trained and experienced staff.

For the Care Inspectorate

4. The Care Inspectorate should review how it can be satisfied that specialist services which are predominantly designed for people with learning disabilities or mental health problems are able to meet the needs of people with autistic spectrum disorders placed in their care.

Discharge planning

For health boards and integrated joint boards

5. Bodies discharging people with complex needs to specialist services should ensure that there is a robust and safe process of preparing for discharge and managing the handover to specialist services, including
 - formal discharge planning meetings, involving all relevant staff including from the care provider, sufficient to ensure effective handover of information and allow good quality care and treatment to be provided following discharge
 - an agreed medication care plan where there is a complex medication regime in place, to assist the care provider in managing medication, and to make clear whether changes to medication should be through the RMO or the GP
 - information immediately available at discharge to the GP followed by a comprehensive discharge letter within locally agreed timescales, usually within 7-10 days. In complex cases the consultant psychiatrist should telephone the GP prior to discharge to discuss the case
 - clear follow-up and secondary care arrangements which are understood by all parties involved.

For health boards and Responsible Medical Officers

6. Where an individual remains subject to the Mental Health Act following discharge, for instance on suspension of detention, the RMO, or their clinical team, unless clearly agreed otherwise, should be the first point of contact by support staff regarding medical treatment that is not standard in general practice. The RMO should be satisfied that he or she is able to carry out their Mental Health Act responsibilities for the care and treatment of the individual following discharge.

For Scottish Government

7. Arrangements for registration with GPs should be reviewed to ensure that information can be passed on and responsibilities agreed before a person moves to a new service, not only after the move has taken place

Investigation of serious incidents

For Scottish Government

8. The review to be held into the investigation of deaths of detained patients and in-patients under section 37 of the Mental Health (Scotland) Act 2015 should also consider deaths by suicide of patients who are under suspension of detention.

For Health Boards

9. Pending the outcome of the s37 review, NHS Boards should ensure that a critical incident review takes place when an individual dies by suicide while on suspension of detention or a community based Compulsory Treatment Order, or within 12 months⁶ of moving from in-patient mental health care to community based residential services.

Development of services for people with autistic spectrum disorders and complex needs

For the Scottish Government and the Autism Strategy Governance Group

10. The Scottish Government should audit the availability of specialist services for individuals with highly complex needs who are not appropriately accommodated in learning disability or mental health settings, and identify how gaps can be filled.
11. The Autism Governance Group should review the issues raised by this case and consider the implications for the implementation of the current autism strategy, particularly what more can be done to ensure staff in mental health and learning disability services are trained to meet the needs of autistic spectrum disorders who use their services.

⁶ See letter to all NHS Board Chief Executives from NHS Healthcare Improvement Scotland, Deputy Chief Executive dated 16 December 2015 for precise requirements

Appendix 1 – Glossary

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|-------------------------------|---|
| Asperger Syndrome | A form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language. (National Autistic Society) |
| Asthenic personality disorder | Now referred to as 'dependent personality disorder'. A person with dependent personality disorder feels they have no ability to be independent. They may show an excessive need for others to look after them and are "clingy". (www.nhs.uk) |
| Autistic spectrum disorder | A lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways (National Autistic Society). |
| Chlordiazepoxide | A sedative medicine used in the treatment of anxiety and alcohol withdrawal. |
| COT | The Community Outreach Team, a team providing psychiatric nursing in the community. |
| CPA | The Care Programme Approach is a formal system whereby all those involved in a person's care, included family and relatives where appropriate, housing, police, social and healthcare workers meet together with the individual to discuss how best to support and care for them. |
| CRISP | Crisis Intervention Support Plan. |
| CT1 | A doctor with 1 year of core psychiatry training. |
| GP | General Practitioner. |
| Haloperidol | An anti-psychotic medication. |
| HASP | Holistic assessment and support plan. |
| IPCU | Intensive psychiatric care units are wards used for individuals whose behaviour cannot be safely managed on acute admission wards. They are often smaller locked units. |
| Lorazepam | A benzodiazepine generally used to treat anxiety. |
| Methotrimeprazine | A low-potency antipsychotic with strong analgesic, hypnotic and antiemetic properties that is primarily used in palliative care. |

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|-------------------------|---|
| MHO | A mental health officer is a social worker who has special training and experience in working with people who have a mental illness, learning disability or related condition. |
| Midazolam | Reducing anxiety or producing drowsiness or anaesthesia before certain medical procedures or surgery. |
| On pass | Informal term for 'suspension of detention'. |
| PRN | As required medication – literally “pro re nata” which means “as the thing is needed”. |
| Procyclidine | A medication which can be given to reduce the side effects of antipsychotic treatment given for schizophrenia. |
| Quetiapine | Atypical antipsychotic, approved for the treatment of schizophrenia. |
| RMN | Registered Mental Health Nurse. |
| RMO | Responsible Medical Officer, a senior psychiatrist who has overall responsibility for the psychiatric care of their patients. |
| SATS | Safe and Therapeutic Interventions are a suite of nursing interventions Health Board A use in the management of agitation or aggression. |
| Specified Person | Part 18 of the Mental Health Act sets out how restrictions which may be imposed upon a detained individual's correspondence, use of telephones or in relation to their safety and security, can be authorised. The individual is made a “specified person”. |
| Suspension of detention | Authorisation by the RMO for a detained person to spend time outside hospital grounds. |
| T3 Form | A T3 form was used (in this case) as the RMO was required by section 240(3) of the Mental Health Act to provide a certificate for all of Ms MN's medical treatment, because he considered she was refusing consent or was incapable of consenting to the treatment. |
| Zopiclone | A medication used in the treatment of insomnia. |

Appendix 2 - Care Inspectorate inspection of the care home

In September 2012 the Care Inspectorate visited the care home and reported that it scored highly in the three areas inspected. It noted:

“At the time of the inspection the service was not operating to capacity. The service was aware of the staffing schedule agreed with the Care Inspectorate at the time of registration; however they had reduced the staffing to reflect the vacancies in the unit. The service had not undertaken a dependency assessment to assist them to determine the correct staffing requirements based on the needs of those living in the service”.

Requirements:

1. The provider must ensure that there are suitable qualified numbers of staff both in number and in skill on duty in the care home at all times to meet the needs of service users.

The service has had a high turnover of staff in recent months which has had an obvious impact on the service. However we were satisfied that the service have followed safer recruitment practices and were at differing stages of the process for newly recruited staff. Newly recruited staff received an induction to their new employment which included shadowing existing staff and training in key area to meet the needs of service users.

Although the staff team had had a lot of disruption through the high turnover. Those spoken to were very positive about the quality of service delivered to those living at the care home. They describe a positive team spirit and told us that they felt supported by the management team to provide good quality care.





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