Serious Case Management Review

A Thematic Review of Self-Neglect

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Contents

1. Introduction

1.1. This Thematic Serious Case Management Review (SCMR) concerns the lives of seven people who all died in circumstances of self-neglect.

1.2. Each person's death was in sad circumstances. Not all those people were well known to IOM services. The Isle of Man Safeguarding Board (IOMSB) wanted to understand how effectively services and communities in the IOM work together to support people who may be self-neglecting and use that learning to make improvements.

2. Context of Serious Case Management Reviews

2.1 The IOMSB will convene a SCMR in circumstances where:

(a) there is cause for concern about how the Safeguarding Board, it's partner agencies or any other relevant body have worked together to safeguard the vulnerable adult, and
(b) a vulnerable adult has died or suffered serious harm and
(c) where abuse or neglect is known or suspected.

2.2. The IOMSB judged that these criteria were met for a man 'Robin'. Robin was in his eighties when he died. Robin was known to several different agencies.

2.3. The IOMSB wished to maximise learning by also exploring the circumstances of six other people who died in IOM within the last two years, also in conditions of self-neglect. Each death is a tragedy for the family, friends and agencies who knew the person. Although the circumstances of those people's deaths had not met criteria for a SCMR, the IOMSB felt it appropriate to make proportionate enquiries to understand common themes that could extend learning.

2.4. The purpose of SCMRs is to promote learning and improvement with the aim of reducing risk of deaths or serious harm to others. A SCMR is not about apportioning blame. The review seeks to understand the systems in which agencies operate and explore factors that aid and present barriers to delivering best practice.

2.5. The IOMSB commissioned an independent author, Sylvia Manson, to lead the review. The reviewer is wholly independent of IOMSB and its partner agencies. She is an experienced chair and author of Safeguarding reviews and has led other reviews in IOM including a quality improvement review of Safeguarding Adults.[1] She has a professional social work background, managing Health and Social Care, specialising in mental health and safeguarding.

[1] Isle of Man Safeguarding Board Review of Multi-agency Safeguarding Adults Arrangements, Interim Report 2020; Available through IOMSB [Accessed May 2022]

3 Terms of Reference and Methodology

3.1. Terms of Reference

3.1.1. The aim of this thematic SCMR is to understand the experience of those seven adults whose lives ended in circumstances of self-neglect. The learning will be used to develop the responses to self-neglect by IOMSB partner agencies.

3.1.2. Objective is to:

- Identify commonalities in precipitating factors that led to a person self-neglecting
- Hear from family/carers/friends about their experience, what interventions by agencies helped and what could be improved
- Understand the challenges, enablers, and barriers that different agencies and their frontline practitioners experience in responding to self-neglect.
- Identify and extend good practice
- Make recommendations to the IOMSB for further development of strategic and practice resources for self-neglect

3.1.3. The thematic SCMR explored whether there were opportunities for services to work together to reduce risks from self-neglect.

3.1.4. 1. The review explored how well best practice factors in working with self-neglect were evidenced[2]

Practice Factors Most Successful in Self Neglect	
Engaging	**1.** Time to build rapport and a relationship of trust, through persistence, patience, and continuity of involvement
	2. Trying to 'find' the whole person and to understand the meaning of their self-neglect in the context of their life history
	3. Working at the individual's pace, but spotting moments of motivation that could facilitate change, even if the steps towards it were small
Working with Risk	**4.** Understanding the nature of the individual's mental capacity in respect of self-care decisions
	5. Having an in-depth understanding of legal mandates providing options for intervention
	6. Being honest, open and transparent about risks and options
Working Across Agencies and Communities	**7.** Creative and flexible interventions, including family members and community resources where appropriate
	8. Effective multi-agency working to ensure inter-disciplinary and specialist perspectives, and coordination of work towards shared goals.

[2] Social Care Institute for Excellence, Braye., S, Orr, D., and Preston-Shoot, M., (2015), *Self-neglect Policy and Practice: Research Messages for Managers*, Available from: https://www.scie.org.uk [Accessed January 2022]

3.1.5. 2. The review also examined how practitioners were supported by systems and resources to work with people who are self-neglecting[3]

Organisational Factors to Support Practice in Self Neglect	
Systems and Structures	**1.** A clear location for strategic responsibility for self-neglect
	2. Data collection on self-referrals, interventions and outcomes
	3. Clear referral routes to respond to self-neglect
	4. Systems in place to ensure coordination and shared risk management between agencies
Supporting Workforce	**5.** Time allocations within workflow patterns that allow for longer-term supportive relationship-based involvement
	6. Training and practice development around the ethical challenges, legal options and skills involved in working with adults who self-neglect
	7. Supervision systems that both challenge and support practitioners

3.1.6. 3.The SCMR also analysed practice against the Safeguarding Adult Principles[4]:

Empowerment:	Understanding how agencies maximised decision making, involvement and respected individuals' views – Making Safeguarding Personnel. How effective was assessments of decision making i.e. considering capacity or undue influence impacting on decision making?
Prevention:	Examining earlier opportunities to engage and reduce risk of future harm
Protection:	Considering how well risks were understood and the effectiveness of risk reduction measures.
Proportionality:	Weighing whether responses were reasonable and proportionate to the risks of harm and within legal parameters – least restrictive of rights and freedoms
Partnership:	Reflecting on the quality of inter-agency interactions toward coordinated care planning and safeguarding responses.
Accountability:	Understanding accountable practice in line with statute and Safeguarding Adult procedures Exploring whether the appropriate level of professional expertise was applied, along with use of supervision and management consultation

[3] Ibid
[4] The Safeguarding Adult Principles are contained in the Care Act 2014 Statutory Guidance as underpinning all safeguarding work. The principles have been incorporated into IOM safeguarding adult policy and procedures.

3.2. Methodology

3.2.1 The review sought to maximise learning in a way that was proportionate and made most effective use of agency resources and public funds. This combined:

3.2.2. 1. Reports from agencies relating to their involvement with the seven people:
- Narrative report/analysis and chronology of agencies involvement with Robin
- Summary overview reports of agencies involvement with the six other people included within this thematic review

3.2.3. 2. Learning events:
- Learning event to hear the views and perspectives of practitioners/agency representatives involved with Robin.
- Learning event with IOMSB/relevant agencies practitioners/managers involved in working with self-neglect.

3.2.4. Understanding the experiences and perspectives of those most closely involved is fundamental to learning. The review sought to involve family and friends of those seven people who are the subjects of this thematic SCMR. The author is grateful to the people who felt able to contribute, including neighbours and friends and family members. Their perspectives are included within the report.

3.2.5. Pseudonyms have been used to protect the identities of those involved. Robin's niece chose his pseudonym. Dates have been generalised and the names of smaller agencies have also been anonymised.

Participating Agencies	
Manx Care: Health Services	IOM Constabulary
Manx Care: Adult Social Care/Adult Safeguarding Team	IOM Fire and Rescue
GP Practices for the seven people	IOM Environmental Health
Independent Sector care agency	Housing Providers
Volunteers Befriending Scheme	

3.2.6. The thematic review covers a period from April 2018 to February 2022. This spanned the last 2 years of each person's life. However, agencies were asked to provide any historical information from the person's background that was relevant to the terms of reference. The thematic review also benefitted from the Coroner's reports and findings relating to the individuals' deaths.

3.3. Structure of Report

The report is structured as follows:

- Section 4 gives the context of self-neglect and what is known to be best practice in working with self-neglect.
- Section 5 provides background, key events for the seven people, and draws out learning themes relating to practice factors
- Section 6 considers the wider systems factors that aid or present barriers to practice, and some recent changes and opportunities
- Section 7 provides a conclusion.
- Section 8 makes recommendations for the IOMSB and its partner agencies.

4. Context of Self-Neglect

4.1. 'Self-neglect' refers to a range of behaviours. It may include lack of self-care in areas such as personal hygiene, dietary needs and health needs. Self-neglect may also relate to lack of care to one's environment –for example unsafe or unhygienic home conditions; clutter arising from hoarding resulting in risks to health and safety and fire risks. Self-neglect may be shown in refusal of assessments and interventions by services that may alleviate the issues.

4.2. Defining self-neglect can be open to interpretation, with subjective judgements about what are 'acceptable' standards. Practitioners need to make professional judgements about levels of risk but weigh this as part of wider considerations about the adult's wellbeing.

4.3. A state of wellbeing is dependent on many factors - physical and mental health, occupation and economic security. Wellbeing is also dependent upon social and psychological factors including dignity, protection from abuse and neglect, and control by the individual over their day-to day life.[5]

4.4. Wellbeing is an individualised concept. Individuals' may put different weight on the factors that combine to give them wellbeing, for example some may put greater emphasis on safety and security, where others may put more weight on retaining independence even though it may compromise safety and security.

4.5. Safeguarding Adults should be founded on Making Safeguarding Personal[6] (MSP). This recognises individuals' rights to self-determine how they live their lives. Safeguarding interventions need to be person centred and guided by the adult toward the outcomes they want i.e. promoting their wellbeing. MSP can be challenging to achieve where a capacitous adult's resistance to care, leaves them at high risk

[5] The description is drawn from definition in the Care Act 2014 Department of Health Care and Support Statutory Guidance Issued Under the Care Act 2014 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/315993/Care-Act-Guidance.pdf

[6] The Care Act 2014 Statutory Guidance endorses Making Safeguarding Personal. Whilst the Care Act is not statute in the IOM, the Board has agreed to adopt the key principles as good practice following national guidance. Local Government Association: Making Safeguarding Personal https://www.local.gov.uk/our-support/our-improvement-offer/care-and-health-improvement/making-safeguarding-personal [Accessed Feb 2022]

from self-neglect. Respect for self-determination needs to be balanced with duty of care. [7] This requires taking reasonable (and lawful) steps that are proportionate to risk, working with the person to reduce risks of harm.

4.6. All of this makes for a complex context for practitioners to work within. A recent review of Safeguarding Adult Reviews[8] in England[9] highlighted that self-neglect was the most common concern that had led to the review being held, accounting for 45% of all reviews.

4.7. Mental Capacity is a key factor when working with self-neglect – determining whether a person has the mental capacity to make decisions (and then to execute those decisions) about their self-care. This is central to the rights of the adult to make decisions, even where others may view those decisions as unwise. Where the adult lacks the relevant capacity, it confers duties on others to make decisions for the adult in their Best Interest. However, this still requires taking account of the adults past and present views and wishes - understanding what 'wellbeing' means to them; and working in the least restrictive way of the adult's rights and freedoms.

4.8. The IOM does not yet have capacity legislation in place. At the time of the review, the IOM Capacity Bill was in its second reading within the Parliamentary process. The IOM did have a capacity policy in place[10] but without the weight of statute.

4.9. The IOM also had policy and procedures on managing self-neglect. [11] This set out steps for engaging, risk assessment and coordinated multi-agency working. It also referenced a self-neglect panel, an escalation pathway in respect of safeguarding thresholds and risk appraisal. As is described in sections below, the policy was not routinely being used and the self-neglect panel was no longer operating.

4.10. IOM was also working to the Department of Health and Social Care Interagency Safeguarding Adults Policy and Adult Protection Procedures 2018 – 2020. At the time of the review, this procedure was under review. Section 6 discusses further the systems that support practice.

4.11. Research has highlighted factors that are most successful in working with self-neglect, and the systems that need to support practice.[12] These have formed the basis of the terms of reference for this review, as set out in 3.1 above. The following sections will use these factors to analyse the responses to the seven people subject of this review.

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[7] LGA and ADASS Myths and realities about Making Safeguarding Personal 2019 https://www.local.gov.uk/sites/default/files/documents/25.144%20MSP%20Myths_04%20WEB.pdf [Accessed January 2022]

[8] Safeguarding Adult Reviews are equivalent to a SCMR

[9] Local Government Association: Analysis of Safeguarding Adult Review April 2017- March 2019; October 2020

[10] Isle of Man Government Department of Health and Social Care Capacity Guidance v2018

[11] Isle of Man Department of Health and Social Care Self-Neglect Policy and Procedures 2017 https://www.gov.im/media/1358673/self-neglect-updated-policy-and-procedures-sept-2017.pdf

[12] Social Care Institute for Excellence, Braye., S, Orr, D., and Preston-Shoot, M., (2015), *Self-neglect Policy and Practice: Research Messages for Managers*, Available from: https://www.scie.org.uk [Accessed April 2022]

5 The People this Review is About

5.1 Robin: Background and Key Events

5.1.1. Robin was a man in his eighties who died of hypothermia. At the time of his death, the conditions in which Robin was living were unsanitary, the building was unsafe with very basic provision of essential utilities such as heating and hot water. Robin's house was often cold as he declined to put heating on despite advice. Robin's self-care was very poor. Robin had lived in this way for many years but lately his health had declined.

5.1.2. Robin had been born in that house and lived there with his parents. Robin's father had died when he was a young man and his mother died around 20 years ago. Robin's (second) cousin described Robin's mother as a strong-willed person who exerted control over many aspects of Robin's life. She reported that he was largely confined to home and did not have the opportunity to develop skills for daily living or the freedom to go out for work or social relationships.

5.1.3. Robin struggled to come to terms with his mother's death. The family home had been kept in pristine condition, but it gradually fell into disrepair and Robin's self-care deteriorated.

5.1.4. Robin had no other family members on the IOM but had very regular phone contact from his cousin. She lived in the UK and would visit him annually. However, Robin took efforts to avoid her visiting his house.

5.1.5. Over the years, the house conditions deteriorated. When Adult Social Care (ASC) became involved in 2011, the house was in a near derelict condition. When Robin's cousin eventually saw the inside of his home in 2015, she described dire conditions. The floorboards, walls and chimney were crumbling, there was no heat or hot water, and the only source of electricity was a single socket.

5.1.6. Robin appeared to have financial means but preferred to keep his money in cash in the house. Robin's cousin described him as kind and generous, but he worried about not having money, so spent very little on himself. He hated any waste and salvaged out-of-date food from supermarket bins. His cousin described him reusing dirty plates for months on end because he didn't want to (or was unable to) wash up.

5.1.7. Robin's cousin was clear that Robin was content in the way that he lived although she acknowledged this may be difficult for others to contemplate. Robin's cousin would periodically buy him new clothes, but he preferred to wear his old clothes that were very dirty.

5.1.8. Robin's lack of self-care could lead to physical health problems, such as skin integrity/wound management and stomach upsets. Robin had several health needs. As a young man, he had had a motorbike accident and required a metal plate to be fitted in his head. It is not known whether there were any residual problems from this accident. In his later years, Robin had developed hypertension and chronic kidney disease. Robin also had osteoarthritis in the knee and was unable to walk without aids. Robin engaged well in treatment from his outpatient clinics, Community Health Services and GP.

5.1.9. Robin was also well known to other agencies. Historically Robin had had some contact with the Fire Service for fire safety tests, and with Environmental Health due to rat and mice infestation. Robin was

also known to ASC and had weekly contact with a care agency. He also had informal support from his neighbour and a Community Police Officer along with a volunteer befriender although their contact had reduced during the Covid pandemic restrictions.

5.1.10. Robin seemed to enjoy the company of professionals and volunteers and they described his warm, dry sense of humour. However, Robin was very clear about what care and support he was prepared to accept. He remained adamant he wanted to remain in his own home and did not require any additional support.

5.1.11. In the time leading up to Robin's death, ASC had recently become reinvolved, following a referral by his GP. Contact had been made but sadly, Robin died before a formal assessment could be carried out.

- Key events

5.1.12 Robin was first known to Adult Social Care in **2001,** referred by his GP. The referral noted that he was living in squalor, had poor mobility, was isolated relying on informal networks and was resistance to help and support. ASC passed the referral to their Homecare service (now Community Support Services CSS).[13] There are no records of any follow up.

5.1.13. In **2008**, ASC had contact from a cousin expressing concern regarding Robin's living conditions. Information was posted out to the relative for discussion with Robin. No further action

5.1.14. A year later, a neighbour contacted ASC reporting concerns about Robin's living conditions. A Senior Social Worker carried out two home visits (unannounced) without gaining access and sent a letter but got no response. There was no further action.

5.1.15. The following year (**2011**), Robin sought help from ASC to sort out affairs. He described being "*in a mess but not knowing where to start*". He was allocated a Social Worker (SW) from the Older Persons Community Social Work Team (OPCSWT). They found very poor conditions in the structure of the property, lack of utilities and unsanitary conditions. Robin's house had a rat infestation. He had sores on his legs as rats had eaten away the padding in his mattress

5.1.16. This SW remained involved for the next 10 years trying, with limited success, to improve Robin's living conditions. They negotiated with Robin to have some periods of short-term respite care during **2012 – 2014**. The SW also arranged for Robin to occasionally attend residential units to have a bath. However, Robin voiced how much he hated this experience and stopped going.

5.1.17. **In 2013** an Environmental Health pest control officer treated a rat and mice infestation. (It is not clear where the referral had originated)

5.1.18. In **2015**, Robin's SW contacted his cousin to discuss the state of his property. The cousin's recall of this, was that Robin was at risk of being moved from his home as it was in such poor condition. Robin reluctantly accepted the need for work to be done and moved to respite care for 2-3 weeks while his cousin carried out some major renovation work. There was an infestation of mites and Robin's cousin

[13] CSS is part of Adult Social Care. CSS is a service provide packages of support to enable people to live at home and to retain their independence – this can include practical tasks such as shopping, personal care, food preparation and medication prompting

acted on advice to burn the contents, replacing everything with new. When Robin returned home, he was highly distressed about what had happened to his belongings. He stopped all contact with his cousin for the next 6 months.

5.1.19. In **2016**, Robin's SW arranged for a volunteer befriender. The befriender visited regularly, helping him with tasks such as bill paying. They maintained their relationship right up to Robin's death.

5.1.20. In **2016** a member of public contacted the police, concerned about Robin's living conditions. The Police Officer who attended was concerned by what he found, but Robin was adamant about remaining in his home. The officer contacted ASC and liaised with his SW. This Police Officer remained involved on an informal basis – visiting regularly and providing practical help over the next 3 years. The officer worked with Robin's SW to try and encourage change but with limited affect.

5.1.21. In **2019**, the ASC Community Support Service (CSS) commissioned a Health and Safety report of Robin's property. The report highlighted Health and Safety risks in the property and recommended CSS staff not to enter. Robin dismissed the findings as '*over the top.'* The CSS support plan was revised so that staff would not go into his house but met Robin at his front door. Robin's SW tried to negotiate with him to get some repair work done but without success.

5.1.22. Later that year, a SW assistant carried out a review. Robin had been receiving help from CSS with shopping, cleaning and collecting his pension from CSS. He had been paying for this support and the intention was to transfer this service to a private company.

5.1.23. Robin had been attending outpatient clinic for his kidney condition and District Nurses (DN) were asked to visit Robin for blood tests. The DN's records from their visit in **January 2020** reference dirty conditions in the house, evidence of mice and Robin being unkempt.

5.1.24. In **January 2020**, the SW from OPCSWT ended their involvement as it was felt that there were no identified tasks for the SW. Robin's situation was stable and he was being supported by his befriender and had weekly visits by CSS.

5.1.25. Robin attended his Renal Clinic appointment in **March 2020**. He also was seen by Podiatry who recorded Robin's personal hygiene as poor.

5.1.26. At the end of **March 2020,** the restrictions related to Covid Pandemic began. There were periods when professionals were unable to make home visits to any service user unless in emergency. Robin's befriender and the community police officer were not able to see Robin but maintained contact by phone. Robin maintained his stance that he wanted to remain in his home.

5.1.27. In **April 2020**, an ASC SW assistant contacted Robin. During the pandemic, SW assistants were supporting CSS by providing additional capacity. The SW Assistant arranged shopping for Robin and visited to check his home conditions. Robin also contacted ASC, phoning OPCSWT in **May 2020**, to report he was '*fit and well …just catching up'*. OPCSWT arranged for the local meal service to provide a weekly service as his befriender was unable to visit.

5.1.28. By **June 2020**, CSS recommenced shopping. CSS reviewed Robin's care plan and risk assessment with him. CSS recorded concerns regarding the property and falls risk. Robin was explicit that he understood

the risk of falls and did not want any other help. In **July 2020** CSS transferred their service to a private care provider along with a care plan and risk assessment.

5.1.29. Over the next few months, Robin attended medical appointments for medication review; chronic kidney disease and to receive his flu vaccine

5.1.30. In **Dec 2020**, The fire service contacted ASC. They had attended Robin's house to fix a smoke alarm and were concerned about him. When ASC followed up, Robin minimised the concerns and declined any support, so the referral was closed with no further action. Robin continued to attend to his health care, being proactive in asking for help to attend clinic.

5.1.31. In **May 2021**, Robin was allocated a Named GP. His Consultant Nephrologist was concerned about him and asked the GP to refer him to ASC. The GP spoke with Robin and referred him to OPCSWT. The OPCSWT were also contacted by Police in **June 2021**. Police had made a welfare call to Robin due to concerns by a neighbour. Robin was safe and well, but Police were concerned about his living conditions. When the OPCSWT followed up, Robin confirmed he was receiving weekly support from the private agency and was having contact with his befriender and a neighbour. OPCSWT did not view Robin's needs as a priority, so he was on a waiting list for allocation.

5.1.32. The podiatry service had attended Robin at home in **June** and again in **Sept 2021**. Their records noted his poor conditions at home. Robin also attended the GP Practice, supported by his informal carer and had follow up home visits by DN's.

5.1.33. In **October 2021**, Robin's cousin, wrote a detailed letter to his GP, wanting the GP to understand Robin and his living circumstances. She described his poor living conditions and that he had refused attempts by family to help and his past response to respite care.

5.1.34. The letter detailed the care Robin was receiving from paid agency and volunteers. His cousin believed NHS staff were refusing to enter his property and that Social Services were no longer involved because he had money to pay for services. The letter emphasised the distress it would cause Robin to leave his cottage and his view that he had been born there and that he wanted to die there. The cousin felt that any move '*would kill him*' and urged the GP to avoid hospital admission unless absolutely necessary. Robin's cousin asked to be contacted for any interventions or if his health declined so that she could travel over to support him.

5.1.35. A GP contacted Robin and spoke with his care agency, arranging for them to bring Robin in for an appointment with his Named GP. When Robin attended, he was provided with treatment and given advice about fire safety. The GP Practice put an alert in Robin's records.

5.1.36. In **November 2021**, DN's attended Robin's home for blood tests. A few days later, a GP spoke with Robin's cousin, (with Robin's consent). The cousin reiterated Robin's circumstances and his wish to remain in the property. The GP also spoke with Robin's care agency who agreed that Robin '*would not last long'* if he was forced to move and live elsewhere. Robin was viewed as having mental capacity.

5.1.37. OPCSWT had allocated Robin a SW Assistant (SWA). When they visited Robin at home, the case record referenced living conditions as '*…filthy, cluttered, cold with a strong odour of rodents, urine and faeces and [Robin] noticeably thinner*.' Robin refuted the concerns. The SWA liaised with Community Health

services to try to arrange a joint visit '*to get fresh eyes*' They felt that raising a safeguarding alert would not be in Robin's best interest because it would likely sabotage any chance of engaging with him. (There is no recorded of a joint visit being carried out)

5.1.38. The SWA made enquiries with CSS about accessing a bath or shower at a day centre but were advised this was not possible due to risks to other patients and reduced staffing. The SWA also spoke with Robin's neighbour and befriender. The befriender felt that Robin was emotionally tied to his property and a move would "*finish him off*"

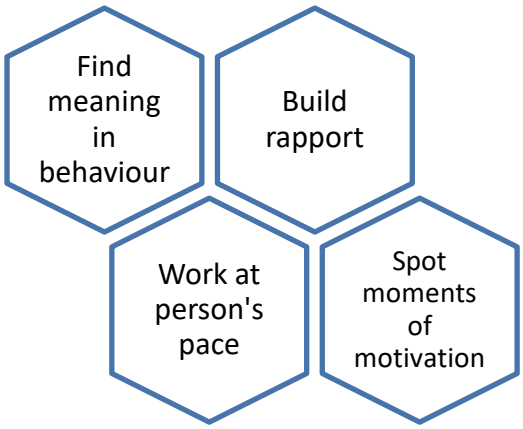
5.1.39. The SWA discussed their concerns with their senior practitioner, and they agreed a visit by a qualified SW. When the SW and SWA visited Robin a few days later, he was not well due to eating contaminated food. Robin remained clear he wanted to live, and die, in his home. The SW arranged a follow up visit for the following week.

5.1.40. The next day, Robin was seen by his Consultant Nephrologist. The Consultant was concerned about his wellbeing and lack of support and wrote to Robin's GP.

5.1.41. The following week, **Dec 2021**, Robin's befriender contacted the SWA as they had not been able to contact him. The SWA spoke with Robin's neighbour and then alerted the Police. Robin's neighbour called round before police attended. Sadly, Robin had died of hypothermia.

Robin: Learning Themes

- Engaging With Adults



5.1.42. Research has emphasised the importance of using a relationship to negotiate small steps toward change. [14] The chronology identifies good practice with key people who had sustained relationships with Robin over many years. Robin had the support of caring and compassionate people – both those engaging with Robin in a professional capacity, and those working informally, such as his befriender and the Community Police Officer who demonstrated great commitment to him.

5.1.43 The ASC author felt that the SW had demonstrated good practice in building a relationship with Robin, demonstrating empathy and a non-judgemental approach, and respecting his autonomy.

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5.1.44. Robin enjoyed the company of people. Establishing a relationship with him was not the challenging issue. The challenge was in using those relationships purposefully to understand the under lying reasons for his behaviours; demonstrating professional curiousity and using this understanding to negotiate change.

5.1.45. There was some good evidence in the earlier years of using moments of motivation. Examples of times when Robin had been unwell or during cold periods, when his SW persuaded him to accept respite care or to go to a residential centre for a bath. However, Robin described how miserable he felt during those times. He described being stripped off as soon as he got through the door, having his hair cut off, shaved and clothes removed. He soon opted out.

5.1.46. Robin's SW described the difficult balance of being tenacious and persuasive with Robin about the need to change his sef-neglecting behaviours, whilst seeking to maintain their relationship. The ASC author was clear that all ASC staff had been extremely caring. They were motivated to help and wanted to do more but were limited by the boundaries put in place by Robin and the fear he might withdraw from services all together. It seems that Robin was very able to voice his wishes and views. However, advocacy can be a helpful resource where a person may feel an imbalance in power. There is no advocacy provision in IOM so this option was not available to practitioners.

Recommendation Arising

5.1.47. The length of engagement demonstrates the ability of the SW to maintain the relationship – the section below 'Working with Risk,' examines how effective this was in addressing risks.

5.1.48. Despite the involvement of so many professionals over the years, it seems that there was limited understanding of the reasons behind Robin's behaviours. There are multiple reasons why people may self-neglect. Robin talked about how important his home and his belongings were but this seemed at odds with lack of care to those belongings as well as to himself.

5.1.49. Robin had had a head injury many years earlier. There were no records that this had affected his functioning. His cousin believed that Robin's way of living was due to lacking the skills for daily living (a consequence of his very controlled upbringing by his mother), rather than any mental health needs. However, there are no records of whether there had ever been a neurological assessment following Robin's head injury as a young man.

5.1.50. Robin had difficulty coming to terms with his mother's death and continued to be tearful when talking of this. Professionals were not aware of the nature of Robin's upbringing. There was no knowledge of whether there may have been a psychological basis for his behaviour, such as trauma. There was also no obvious symptoms of a depression or other mental illness.

5.1.51. Research highlights that depression in older adults is common but recognition rates are lower than for younger people.[15] The effectiveness of psychological treatments for older adults is well established but

[15] Joint Commissioning Panel for Mental Health Guidance for Commissioners of Services for Older People 2017 https://www.rcpsych.ac.uk/docs/default-source/members/faculties/old-age/old-age-jcp-for-mental-health.pdf?sfvrsn=8242f3c2_4 [Accessed May 2022]

are often not fully provided. Where psychological services are provided, older adults are more likely to attend, but GPs are less likely to refer.[16]

5.1.52. ASC records from 2014 note that a referral to mental health services had been considered at that time but when Robin accepted some repair works to his property, the referral was not progressed.

5.1.53. It is not known whether Robin's circumstances would have met the existing critieria for referral to talking therapies or for other mental health assessments. It is quite possible that Robin would have declined a referral had one been offered, given his general dismissive response to people's concerns. However, there was no liaison between the ASC and the GP to explore potential reasons for his behaviour.

5.1.54. Access to psychological and mental health assessment is an important component in working with self-neglect. Assessments can be useful if only to rule out functional or organic mental disorders that may be affecting the adult's ability to self-care. However, agencies discussed the limited provision of talking therapies and more specialist resources such as neuro psychologists in the IOM.

Recommendation Arising

5.1.55. Robin was allocated a Named GP in 2021. This is standard practice for older adults and patients with long term conditions, to provide overall responsibility for the patient's care and support. Robin's cousin felt his GP did not really know him well. The GP had no knowledge of Robin's living conditions until they received the letter from Robin's cousin in October 2021. Robin was appropriatly accessing health care so to their knowledge, there were no concerns. Historically, DN's had built productive and consistent relationships with him. The Health author reflected that in the last 2 years, it was difficult to see how DN's used relationships with Robin to address self-neglect concerns.

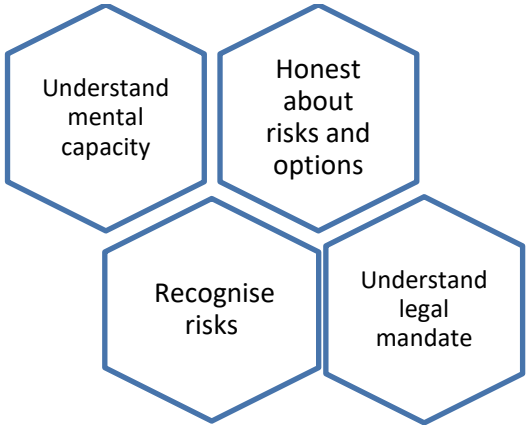
5.1.56. Contributors observed that those strong relationships that Health and Social Care had had in the past, appeared to falter in later years. Some of this was undoubtably related to the Covid pandemic - the restrictions put in place on home visits and the additional pressures on staff. However, the change in contact had pre-dated Covid.

5.1.57. Contributors questioned whether practitioners had simply become demotivated in the face of Robin's ongoing resistance to any changes. ASC's view was that the decision to end the SW's involvement in 2020, was less to do with a change in attitude, as a change in ASC policy. ASC had restructured services and staff felt there was an organisational shift way from long-term casework. ASC commented that closure to the OPCSWT appeared to have been based on Robin being a capacitous adult, a private payer for services and that he was declining any further support. The rationale was that Robin's situation was longstanding, and the care agency; befriender or neighbour could flag concerns if Robin's circumstances deteriorated.

5.1.58. The ASC author reflected that there seemed to be no value placed on the value of low key monitoring as a form of critical assistance. The following section considers the decision to end ASC involvement as part of wider analysis of working with risk and the quality of multi-agency working.

[16] Royal College Psychiatry Suffering in Silence: Age Inequality on Older Peoples Mental Health Care 2018 https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2018-college-reports/cr221 [Accessed May 2022]

- Working with Risk



5.1.59. Section 4 gave an over view of the challenges in working with self-neglect. Partners and public may understandably question why an adult, who appears very vulnerable is 'allowed' to live in unsafe and unsanitary conditions.

5.1.60. The IOMSB endorses and promotes Making Safeguarding Personal. All agencies also need to operate within the law. Safeguarding Adults legislation provides duties on agencies, but as Lord Justice Munby clearly set out, it does not of itself, provide any powers over an adult.[17]

> *'…whatever the extent of a local authority's positive obligations under Article 5, its duties, and more important its powers, are limited. In essence, its duties are threefold: a duty in appropriate circumstances to investigate; a duty in appropriate circumstances to provide supporting services; and a duty in appropriate circumstances to refer the matter to the court. But this is a key message, whatever the positive obligations of a local authority under Article 5 may be, they do not clothe it with any power to regulate, control, compel, restrain, confine or coerce. A local authority which seeks to do so must either point to specific statutory authority for what it is doing….or obtain the appropriate sanction of the court…'*
>
> Para 96, Re A (Adult) and Re C (child): A Local Authority v A (2010) EWHC 978 (Fam), Lord Justice Munby

5.1.61. Working with risk requires

1. A clear analysis of the nature and likelihood of harm(s) to the adult or others
2. Understanding the views of the adult in relation to risk i.e. what is important for their wellbeing and the outcomes they wish
3. Understanding the whole circumstances of the adult's situation including views of other professionals; relevant family /representatives

Exploring viable options for harm reduction i.e.:

4. Risk mitigation

[17] Though this case referenced English law, it applies equally to application of legislation in the IOM

- Strengths, assets and solutions offered by the adult; their family/representatives and community
- Potential mitigating actions/resources from partner agencies

5. Exploring levers for change – the adult's motivations and clarity about the legal mandate

5.1.62. Research highlights the risks of practitioners developing complacency and desensitisation to risks, when working with people in circumstances of self-neglect, particularly over the long term.[18] There is a risk of minimising concerns, simply not acknowledging the high levels of risk that are in plain sight. Formal risk assessment provides the evidence base for accountable practice. It provides the objective counterbalance to practitioners' subjective reactions.

5.1.63. Robin's self-neglect had been long-standing. There was some evidence that practitioners became desensitised and blunted to his day-to-day experience. The long-standing nature of his self-neglect seemed to become a justification for minimising concerns without asking basic questions or taking the necessary follow up actions. The responses to concerns raised by fire service in 2020 and in 2021 when allocation to ASC was not seen as a priority, was an example of this.

5.1.64. There were significant gaps in the quality of risk assessments and the risk management plans throughout the period of involvement of all services so there was no objective baseline to challenge the apparent blunted responses from practitioners.

5.1.65. The ASC report author highlighted that there was a lack of formal assessment undertaken by OPCSWT during their period of involvement. The last update to a risk assessment had been in 2014. In the weeks preceeding Robin's death when OPCSWT had re-engaged, the plan had been to carry out a full social work assessment and risk assessment. However it was still not clear when this would occur and a qualified SW had not been allocated. ASC highighted that there had been over-reliance on able, but unqualified SWAs from 2018.

5.1.66. ASC also recognised the OPCSWT had tried to work with risk over the years of their involvement. There are records of long discussions with Robin about the nature of risks. OPCSWT were working on the basis that Robin had mental capacity to make informed choices and gentle encouragement was the only means to mitigate risks. Their records referred to Robin as having full capacity. While there was no indication that Robin had any impairment to the functioning of the mind or brain, there was no formal capacity assessment.

5.1.67. Although the IOM mental capacity policy[19] directs a presumption of capacity, a formal assessment of capacity (decisional and executive functioning[20]) should be carried out where an adult is acting in a way that may question their ability to make decisions, even if only to eliminate lack of relevant capacity as a possible explanation for behaviours. Having capacity, and the right to make 'unwise decisions' does not mean agencies can just walk away where the capacitous adult's decisions leave them at high level of risk. Duty of care requires sustaining engagement – using assertive outreach techniques for purposeful

[18] Day, McCarthy et al 2017 Self-Neglect in Older Adults: A Global, Evidence-Based Resource for Nurses and Other Healthcare Providers https://www.researchgate.net/publication/320191009_Self-Neglect_in_Older_Adults_a_Global_Evidence-based_Resource_for_Nurses_and_Other_Healthcare_Providers [Accessed August 2022]
[19] IOM Mental Capacity Policy
[20] Executive functioning refers to the ability to think abstractly, integrate inputs such as situation and memory, to put a decision into action

engagement and working across agencies to try and reduce risks. There is a need to extend training in mental capacity.

Recommendation Arising

5.1.68. It is worth noting that even had a capacity assessment found that Robin lacked capacity for the relevant decision(s), any interventions would need to be based in his Best Interests – this includes considering the adult's past and present views and wishes, the views of carers and others involved. It is questionable whether a Best Interest based decision would have endorsed Robin forceably being moved out of his home, given the strength of his views and the requirement for actions to be the least restrictive of his rights and freedom.

> *'…Physical health and safety can sometimes be bought at too high a price in happiness and emotional welfare. The emphasis must be on sensible risk appraisal, not striving to avoid all risk, whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as the price appropriately to be paid in order to achieve some other good – in particular to achieve the vital good of the elderly or vulnerable person's happiness.*
>
> *What good is it making someone safer if it merely makes them miserable?'*
>
> Re MM (An Adult); Local Authority X v MM [2007] EWHC 2689 (Fam)
> Lord Justice Munby

5.1.69. Best Interest decisions could feasibly have enabled less restrictive intervention such as an increased care package and arranging repairs to Robin's property. However, in the absence of a Mental Capacity Act, this would still need legal sanction.

5.1.70. There was some indication that ASC considered other legal levers, for example, liaison with Environmental Health to explore their legal sanctions. There was also discussions with some other agencies such as Community Health (who had been providing District Nursing) to try and address risks associated with Robin's health.

5.1.71. There was no referral through Safeguarding Adult procedures. The reasons are unclear. It may be that self-neglect was not seen as a safeguarding matter, but there was also reference made to not viewing Safeguarding as the appropriate route - it is not clear whether this decision was endorsed through line management.

5.1.72. There was an apparent absence of managerial over-sight to assure practice standards, including Safeguarding Adult considerations were met. ASC management should have provided scrutiny to assessments and endorsed/questioned risk management plans including assuring self-neglect guidance and Safeguarding Adult policy was followed and providing supervision to counter risks of desensitisation. Management did endorse (and encouraged) the decision to end SW involvement in 2020. It is not clear what scrutiny was given to the planned closure. It appears that other agencies such as GP and Community Services, were not consulted or informed about the closure and nor was there a clear contingency plan to manage residual risks. Robin's befriender service was a main player in his continuing support. They did not feel in a position to challenge the way in which Robin continued to live, having been told early on that Robin had capacity so was able to choose to continue to live that way.

5.1.73. One function of managers is to seek solutions where there are barriers to care. An example where managers could have helped related to funding requirements. Robin had been paying for his care. He did not believe he needed additional support so was not prepared to pay more. It is not clear whether Robin would have accepted additional services, if he were not required to pay. It seems this was never considered as an option. ASC does need to be equitable in applying criteria for charging for care services. Nonetheless, there needs to be some discretionary criteria for exemptions. There was no protocol for this in DHSC/Manx Care. The new Manx Care Executive Director has identified this as an area the service needs to address.

Recommendation Arising

5.1.74. CSS had involved Health and Safety in 2019 to assess risks from the home environment. This led to a directive for staff not to enter his property. This action met the duty of care to CSS staff but the ASC author observed there was no clarity about who else within DHSC/Manx Care the directive applied to or who the information should be shared with – notably Health professionals, his befriender and the Community Safety Officer were all visiting Robin at home. It is also not clear how managers ratified their duty of care toward Robin i.e. how the ability to continue to manage risks was affected by the changed care plan and what mitigation was put in place. The ASC author highlighted a lack of operational policy and guidance to support this situation.

Recommendation Arising

5.1.75. The decision by CSS to transfer Robin's care to a private agency, appeared to be purely a practical measure to transfer his paid support to another service provider. This decision did not sufficiently consider the value of CSS's role as a service within ASC and their continued duty of care i.e. redressing risks, monitoring and escalating signs of deterioration. This was an important aspect of ASC's accountability in safeguarding an adult with significant self-neglect risks. The private provider had no involvement or requirement to be involved with other agencies and no regulatory requirements relating to safeguarding responsibilities.

5.1.76. Manx Care has reflected on the value of in-house provision, in working with people with more complex care needs, including self-neglect. The Manx Care Executive Director has identified this as an area to develop.

Recommendation Arising

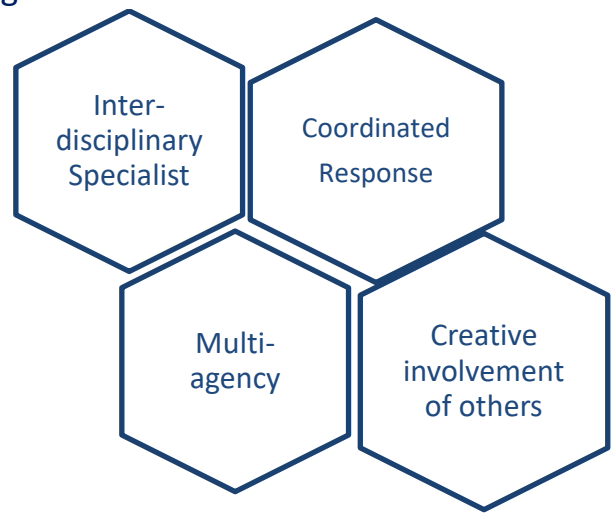
5.1.77. CSS did complete a needs and risk assessment in July 2020. The risk assessment listed hazards and confirmed with Robin that he understood the consequence of his decisions, for example, increased risk of falls. It was shared with the private care agency. CSS's practice also fell short of assessing capacity; formulating a risk management plan and triggering multi-agency responses in line with the Self Neglect and Safeguarding Adults policy.

5.1.78. The author of the Health report to this review also highlighted learning. Contrary to Robin's cousin's understanding, DN's and Podiatrist had been visiting Robin at home. Both services recorded concerns about Robin's lack of self care and the poor conditions of the home but took no further action. There was no risk assessment or management plan. Despite the abject conditions in which Robin was living, none of the health professionals appeared to consider his self-neglect as a safeguarding issue. There was no onward referral through the Self -Neglect policy or Safeguarding Adult procedures. Health professionals became task orientated and desensitised to the high levels of risks that were in plain sight.

5.1.79. The author of the Health report questioned whether Robin's acceptance of health care, was viewed as evidence he could make his own decisions. As noted, upholding a person's rights to self-determine their affairs does not eliminate the duty of care to take reasonable steps to reduce risks from self-neglect.

5.1.80 Alongside the risks of practitioners becoming desensitised to self-neglect, over time, practitioners may develop a sense of hopelessness and develop compassion fatigue[21] where their continued efforts seem to have little impact. Individual practitioners who had known Robin over the years, may have felt at a loss to know how to affect any change. The following section discusses the added value that multi-agency working could have offered.

- Working Across Agencies and Communities



5.1.81 Robin had an extensive network of professionals and informal support through the community and his cousin. Collectively this offered great potential for a multi-agency response. This network could have brought together this expertise and individuals'knowledge of Robin. It was an opportunity to explore the perceptions of his circumstances, his strengths, assets and risks. It was an opportunity to search for creative solutions and develop a coordinated plan with Robin, to reduce risks. It was also a mechanism to share responsibility for risks that remained. Unfortunately, this potential was not used. At no time, was this network brought together.

5.1.82. There were some pockets of joint working, for example, OPCSWT working with Community Services; Police and Environmental Health but this was primarily in the earlier years. There were also some examples of good practice in later years, for example, the SWA speaking with Robin's befriender and carer. The SWA had also tried to arrange a joint assessment with Community Services in the weeks before Robin died – it is unfortunate that this was not facilitated.

5.1.83. There was a lack of a cohesive response from Health services. The Health author commented on silo working and a lack of partnership engagement. Robin's GP had been alerted to general concerns about his wellbeing by a Consultant Nephrologist and information sharing between them was good. It was positive that the Consultant was taking a broader holistic approach to Robin's wellbeing. The Consultant could have referred directly to ASC for support, notifying the GP. The Consutant was not aware of

[21] Ibid

Robin's home circumstances and the extent of self-neglect. Community Health services had attended Robin at home but had not shared their concerns about Robin with his GP, nor made a Safeguarding Adult notification.

5.1.84. There was no communication from ASC to the GP about his self-neglect or the concerns raised by others agencies such a Police and Fire Service. The GP remained unaware of any concerns until Robin's cousin wrote to them in 2021. It was good practice for the GP to gain Robin's consent to speak with his cousin on receiving the letter; arranging to see Robin and speaking to his care agency. However, this did not lead to convening a multi-agency meeting, using the Self-Neglect policy or Safeguarding Adults policy.

5.1.85. Robin's cousin played a key role in his life. She had had past contact with ASC but would have valued greater contact with services. There were missed opportunities by all agencies to involve Robin's cousin more in care planning. Research has highlighted the value that Family Group Conferences can bring in Safeguarding Adult work.[22] This is under used in IOM.

Recommendation Arising

5.1.86. Information sharing is often posed as a barrier to multi-agency working, despite the permissive provisions within General Data Protection Regulations. (section 6 references guidance that the IOMSPB has recently developed relating to this.) It is cited as a main area of learning in a thematic review of Safeguarding Adult Reviews (the term for SCMR's within the UK).[23] Robin readily consented to information being shared between professionals and for professionals to talk with his informal carers and cousin. Despite this opportunity, there was a lack of multi-agency working.

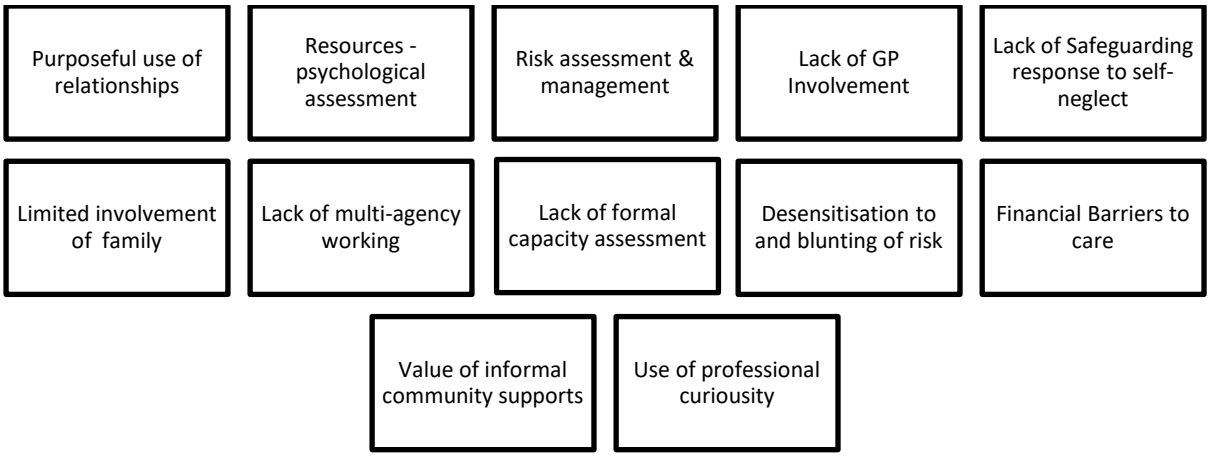
5.1.87. It is not possible to say whether robust risk assessments and multi-agency safeguarding response, could have averted the sad circumstances of Robin's death. Robin may well have continued in his warm but assertive way, to dismiss everyone's concerns and decline any futher help.

5.1.88. What we do know is that robust risk assessment and coordinated multi-agency working would have increased the likelihood of success.

5.1.89. Contributors to the review, reflected that the responses to Robin's self-neglect, were not unique. This suggests gaps in the wider strategic factors that should support practice. The following sections, explore those best practice factors in relation to the other six people and then considers some of the systemic barriers that need to be addressed.

[22] Social Care Institute for Excellence Safeguarding Adults: Mediation and Family Group Conferences 2012 https://www.scie.org.uk/publications/mediation/ [Accessed May 2022]
[23] Local Government Association: Analysis of Safeguarding Adult Review April 2017- March 2019; Executive Summary October 2020 https://www.local.gov.uk/analysis-safeguarding-adult-reviews-april-2017-march-2019 [Accessed May 2022]

Robin: Summary of Learning Themes



5.2. Andrea: Background and Key Events

5.2.1. Andrea was a woman of Manx heritage who was in her 40's when she died. Andrea died of broncho-pneumonia, but the Coroner found that self-neglect was a significant factor in her death. Her accommodation was described as in an uninhabitable state at the time of her death.

5.2.2. Andrea had had mental illness since her twenties and was well known to mental health services. She was diagnosed with a schizoaffective disorder though her mental health had been stable for the last few years. Professionals involved had had some concerns that Andrea may have been using alcohol excessively, but this had not been confirmed.

5.2.3. Andrea lived alone in her Local Government Housing flat. In the period leading up to Andrea's death, she had been unable to leave her house and had missed appointments with mental health services.

5.2.4. Andrea was supported by her family. In the months leading up to Andrea's death, her sister had been concerned about her and alerted mental health services. When her Psychiatrist spoke to Andrea, she dismissed the concerns. Sadly, Andrea died three weeks later.

Andrea: Key Events

5.2.5. Andrea had been involved with mental health services since **2000.** Andrea had some periods in inpatient care and then was supported through Community Mental Health Services (CMHS).

5.2.6. Andrea's Community Psychiatrist began working with her in **2003** and remained involved until she died. The Psychiatrist provided regular reviews, at one monthly, three monthly or six-monthly intervals dependent upon Andrea's mental health need.

5.2.7. In **2005**, Andrea was referred to the CMHS for additional support. From that point until 2016, she was offered support by a Community Mental Health Professional (CMHP) – a Nurse and then a Social Worker. Andrea was also provided additional support by Occupational Therapists (OT), helping build confidence

and skills in daily living. A Community Support Worker also visited twice weekly to provide home support.

5.2.8. The level of support varied according to Andrea's mental health and her wishes. In **2011**, Andrea ended her home support as she felt she no longer needed it. By **2015**, the frequency of visits by her CMHP had reduced to three monthly, by mutual agreement.

5.2.9. In **2016**, Andrea's CMHP left the service. Andrea did not wish a new CMHP. Her mental health had remained stable, and Andrea stated her life was as she wanted it. Her Psychiatrist continued to see Andrea for outpatient appointments.

5.2.10. In **Nov 2017**, Andrea's family contacted her Psychiatrist, expressing concerns about Andrea's self-neglect – the state of her property and hoarding. Andrea's sister requested a meeting with the Psychiatrist, but this was declined giving confidentiality as the reason.

5.2.11. In **June 2018** an OT visited Andrea at home to carry out an assessment of Andrea's hoarding. The OT's assessment was that there was evidence of mild hoarding, but no significant concerns. Andrea's mental health needs did not meet criteria for CMHS and she was not eligible for home care services. The OT discussed some aids that may help her bathing and offered a physiotherapy referral, but Andrea declined.

5.2.12. Andrea was seen by her Psychiatrist at outpatient clinic in **Sept 2018.** Her mental health was stable. Andrea then cancelled the next four appointments. Andrea did attend her appointment with her Psychiatrist in **April 2019**. Her mental health remained stable. Andrea told the Psychiatrist that her conditions at home, self-care and hygiene were adequate, but the Psychiatrist noted that objectively, this was '*somewhat lacking*.' The Psychiatrist noted that Andrea had contact with her extended family.

5.2.13. Andrea was being seen at six monthly intervals at this stage. She cancelled her next appointment and the following six rearranged appointments with her Psychiatrist.

5.2.14. In **March 2020:** Andrea's sister contacted her Psychiatrist again, leaving a message '*really worried about [Andrea]…. living in one room and flat is filthy…. [Andrea] has no strength, her hair is matted, and she has not washed for some time.'* Her sister was informed that the information could be noted but no information about Andrea could be shared as Andrea had not completed a consent to share form. Andrea's sister said that Andrea did not want her mother or sister to know what was wrong.

5.2.15. One month later in **April 2020**, the Psychiatrist phoned Andrea and discussed the concerns (without disclosing her sister as the source). Andrea denied any self-neglect. The Psychiatrist arranged a follow up appointment for six months' time. Sadly, Andrea was found dead 3 weeks later.

Andrea: Learning Themes

- ### Engagement

5.2.16. Research from service users' experience, highlights the importance of continuity of care.[24] It was good practice that Andrea had some long-term relationships with mental health services; two key CMHPs over a seven-year period and the same Consultant Psychiatrist for seventeen years.

5.2.17. The records indicate that mental health services worked to try and support Andrea's activities of daily living and social inclusion although with limited impact. Her last CMHP observed that Andrea had made little use of her CMHP. Andrea did not want what she saw as interference and intrusion in her life.

5.2.18. The CMHP records reference Andrea's seclusion as part of her personality. Her Psychiatrist's assessment was that Andrea's social seclusion was a result of the natural progression of her illness (negative symptoms) and age, as well as under reported but longstanding harmful use of alcohol.

5.2.19. Practitioners were able to maintain a relationship with Andrea. However, it is not clear how practitioners were able to use that relationship purposefully to understand the meaning behind Andrea's behaviours and to use this to lever change.

5.2.20. The author of the Manx Care report to this review observed that there appeared to be no formulation about Andrea's history and a possible psychological basis for her misuse of alcohol and self-neglect, for example experience of trauma. From the records it was not clear to what degree practitioners tried to draw this out and to understand what Andrea wanted to stay safe and well.

- ### Working With Risk

5.2.21. The chronology captures periods when Andrea was withdrawing from services. There were seven occasions when Andrea cancelled or did not attend appointments. It does not appear that mental health services have any 'Did Not Attend' policy to guide decision making when service users miss appointments. This is an omission. Policy needs to set out reasonable steps that respect a person's rights to decline services, with proportionate follow up and risk management relevant to individual circumstances. This was not clear in Andrea's case.

Recommendation Arising

5.2.22. Andrea had the right to decline care. Her Psychiatrist was clear that she had capacity to decide about care and treatment and there were no grounds for compulsion under the Mental Health Act. Mental health services continue to have a duty of care that balances respecting the person's wishes, with taking reasonable steps to maintain engagement in treatment. The level of assertive outreach will be proportionate to the risk presented. Applying assertive outreach techniques, requires skill to avoid the person opting out of services completely if they feel contact is too intrusive. Andrea's mental health had been stable. Mental health services recognised that there had been recurring concerns about Andrea's self-care over the years. They reported that these concerns were mostly not corroborated by home visits by the OT although Andrea did often present as unkempt.

[24] Biringer, E., Hartveit, M., Sundfør, B. *et al.* Continuity of care as experienced by mental health service users - a qualitative study. *BMC Health Serv Res* **17,** 763 (2017). https://doi.org/10.1186/s12913-017-2719-9

5.2.23. A lower level of contact was reasonable but with a contingency plan in the event of any deterioration. It is not clear how effectively Andrea's risk assessment and management plan incorporated involvement of family as a contingency plan. Andrea's extended family were the only point of contact other than Andrea's low-level involvement with outpatient Psychiatry. Her family were therefore in a key position to alert services to a relapse in Andrea's mental health and/or a deterioration in her self-care.

5.2.24. The mental health records do reference Andrea's extended family involvement. Professional guidance[25] references good practice in involving families and carers. It can be challenging where the person does not wish their family to be involved. However, information can be received from family, without disclosing information about the person without their consent and as noted in 5.1., Family Group Conferences[26] can be highly effective in Safeguarding Adults. The response to Andrea's family fell short of expected practice.

5.2.25. The Coroner raised concerns about the Psychiatrist declining to meet with Andrea's family to hear their concerns in November 2017 and recommended the service review guidance on information sharing. It was not until seven months later that an OT carried out a home visit. There is no information of any other follow up actions in the interim.

5.2.26. The assessment carried out by the OT in June 2018, did endeavour to assess the scale of concerns. The OT used a clutter rating scale. This does help to define the nature and degree of hoarding but needs to be used with sensitivity. The Manx Care author noted that the OT had introduced the reason for their visit as being to assess the scale of Andrea's hoarding and to plan interventions. This could be very anxiety provoking for Andrea. Engaging in work on hoarding needs to begin by understanding the reasons for those behaviours and the function it has for the person's wellbeing. For Andrea, it is not clear if she was distressed by the clutter and/or whether she viewed it as serving a positive function in her life, e.g. attachment to belongings rather than people as a psychological defence strategy.[27]

5.2.27. On the second occasion Andrea's family raised concerns, (March 2020), this coincided with a long period when Andrea had missed appointments. This lack of engagement coupled with the family's concerns, and Andrea's history of poor self-care, should have triggered professional curiosity and prompted more assertive follow up. There was a one-month gap between the family raising concerns and any contact being made with Andrea. The response that was made was by phone and was overly reliant on Andrea's self-reporting. Given the very explicit concerns about Andrea's deterioration, a more proactive, home-based assessment was indicated rather than a further outpatient appointment arranged for six-months' time. This response may well have been affected by the Covid pandemic - the uncertainty in those early

[25] NICE Guidance (2011) Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services https://www.nice.org.uk/guidance/CG136/chapter/1-Guidance#care-and-support-across-all-points-on-the-care-pathway [Accessed May 2022]

[26] Social Care Institute for Excellence Safeguarding Adults: Mediation and Family Group Conferences 2012 https://www.scie.org.uk/publications/mediation/ [Accessed May 2022]

[27] British Psychological Society, Understanding Hoarding When our relationship with possessions goes wrong 2016 https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Divisions/DCP/Understanding%20Hoarding%20When%20our%20relationship%20with%20possessions%20goes%20wrong.pdf [Accessed May 2022]

days of restrictions and the additional pressures on all services. However, Mental Health services acknowledged that an earlier contact should have been made. The fact that there had been long term concerns about Andrea's self-care raises questions about the risk of desensitisation and complacency to self-neglecting behaviours.

- Working Across Agencies and Communities

5.2.28. Andrea's care over the years demonstrated multi-disciplinary working but there was limited evidence of working across agencies or applying the IOMSB Self-neglect policy or Safeguarding Adults policy.

5.2.29. There are no records of liaison between Mental Health Services and Andrea's GP. The GP should have been a key player in Andrea's care plan, particularly when she was discharged from CMHS. There is no reference to the GP Practice being informed of concerns about her self-care.

5.2.30. Andrea also lived in Local Government Housing property. Having secure housing is fundamental to wellbeing and sustaining mental health. The Housing sector can provide an essential role in providing Supported Housing for people like Andrea, with additional needs that impact on their ability to sustain a tenancy.[28]

5.2.31. This provision is not applied consistently in the IOM so a resource such as a Housing Support Officer was not available to provide low level ongoing support and monitoring to Andrea. Andrea's social landlord was clear in their response to this review, that their role was limited to annual occupancy reviews and maintenance matters. No concerns were raised about Andrea's ability to manage her tenancy. This response highlights the inconsistencies in approach, particularity for smaller public sector landlords. Section 6 considers the role that Housing could play as part of a wider systems approach to self-neglect.

Andrea: Summary of Learning Themes

Purposeful use of relationships	Psychological informed approaches	Risk management including contingency plans	Lack of GP Involvement	Lack of Safeguarding response to self-neglect
Barrier to involving family - information sharing	Desentisisation to and blunting of risk	Lack of multi-agency working	Gaps in Housing support	need for professional curiousity

5.3. Emma: Background and Key Events

5.3.1. Emma was in her fifties when she died in **2020**. Emma died of sepsis consequent to bronchopneumonia and an overdose of her prescribed pain relief medication. At the time of her death, police noted the poor state of her home with a substantial amount of clutter making most areas inaccessible. This had been a long-standing problem.

[28] One example https://www.lookahead.org.uk/our-services/services-we-provide/mental-health/

5.3.2. Emma lived alone in a Local Government Housing property. She had an adult daughter who was studying away from home but who she had regular phone contact with.

5.3.3. Emma had physical health problems and was prescribed opiate-based analgesics. Emma had experienced multiple losses/bereavements in her life, and she struggled with her mental health. Emma had had a long history of deliberate self-harm and thoughts of suicide when in crisis. Her crisis was often precipitated by psycho-social stress factors. Past assessments had not indicated any formal mental illness. Following a crisis in **2016**, she was assessed as having had an Acute Stress Reaction.[29]

5.3.4. During **2018-2020** Emma contacted police on multiple occasions highly distressed believing people were harming her and stealing from her. Police found no basis for her allegations but were very concerned about her mental health. Neighbours also contacted police on multiple occasions concerned for Emma and/or complaining about her shouting and screaming and bizarre behaviour.

5.3.5. When police attended, they completed Multi-Agency Referral Forms (MARF) due to concerns about her living conditions and her mental health. When mental health services followed up, Emma had a pattern of declining follow up.

5.3.6. In **January 2020** Emma had an acute mental health episode. Her daughter felt Emma's mental health had deteriorated over the last year. Emma was detained for assessment under the Mental Health Act. She was assessed as having an Acute Stress Reaction.

5.3.7. During this admission, Housing officers expressed concern about the state of Emma's property. Emma had been writing all over her walls – this was a vivid expression of her distress. Housing expressed concern about Emma's ability to live independently.

5.3.8. Emma was discharged after four days admission. A CMHP visited her at home and noted the poor state and level of clutter. The Mental Health Crisis team questioned whether Emma had been discharged too early. They made a Safeguarding Adult referral (although there is no record of outcomes from this). A multi-disciplinary meeting was also arranged. The plan was to arrange for Emma to be readmitted on an informal (voluntary) basis. There is no record of this being followed up. A planned follow up professional meeting in May 2020 did not occur.

5.3.9. In **February 2020**, an independent psychiatrist assessed Emma as having a Personality Disorder and episodes of brief reactive psychosis.

5.3.10. Emma continued to be supported initially by the mental health crisis team and was then referred to the CMHS. Emma was viewed as living in a chaotic environment and tended to minimise her difficulties.

5.3.11. From **March 2020**, the Covid Pandemic restrictions meant that CMHP's were unable to visit but they arranged twice weekly phone contact and deliveries from the food bank. Neighbours continued to report concerns about Emma's behaviours. Throughout **March – April 2020** mental health services made further attempts to assess Emma's mental health. However, Emma denied professionals entry as she

[29] A transient disorder that develops in an individual without any other apparent mental disorder in response to exceptional physical and mental stress and that usually subsides within hours or days. Individual vulnerability and coping capacity play a role in the occurrence and severity of acute stress reactions. ICD-10 https://icd.who.int/browse10/2019/en#/F43.0

was concerned about the risk of Covid. The episodes of paranoia and apparent thought disorder continued.

5.3.12. In **June 2020**, police and CMHP visited Emma at home following complaints by neighbours that Emma was throwing glass. There was no response. Sadly, three days later police attended Emma's home again, having been alerted by Housing that her shopping had not been collected from her doorway. Police found Emma's body with medication and what appeared to be a suicide note.

Emma: Learning Themes

5.3.13. Agencies involvement with Emma was extensive. It is beyond the terms of reference to make any detailed analysis of Emma's mental health care and treatment. General observations are made relating to best practice factors in working with self-neglect, whilst acknowledging that Emma's self-neglecting behaviours were inextricably linked to her mental health distress.

- ### Engagement

5.3.14. Mental health services had some challenges in establishing effective relationships with Emma. The records reference Emma had a lifelong tendency to disengage or decline psychiatric services. Emma's last diagnosis was of a personality disorder. Difficulties in forming or sustaining relationships are common traits in many forms of personality disorders.

5.3.15. The records indicate mental health services were often responding to Emma during times of crisis. The model of Crisis Intervention Teams is often one of short-term involvement, with support being offered by various team members. This model is not always the most helpful for people with a personality disorder. Emma had been presenting in crisis repeatedly, but it was not until February 2020, after she was diagnosed with a personality disorder, that Emma had the consistency of an allocated CMHP.

5.3.16. Records reference Emma's involvement with friends and a partner though it is not clear whether they were a protective factor for her. Mental health professionals working with Emma, had information about her history – earlier traumas, bereavements, and losses. They also recognised how current stress factors impacted upon her mental health. Emma's chaotic home environment mirrored her periods of crisis.

5.3.17. It is not clear how Emma's known history was used to inform her care and treatment plan. Psychological therapies are the primary intervention for people with a Personality Disorder, as well as for people who have had an Acute/Post Traumatic Stress Reaction. It is not clear what psychological therapies Emma was offered or accepted, or what work was done with her to help her develop coping strategies and safety plans. Engaging an adult in specialist therapy can take time and be dependent on forming a trusting therapeutic relationship. The review also noted comments from agencies regarding the limited provision of psychological services in the IOM.

Recommendation Arising

5.3.18. There was no information within the records to indicate a change of treatment plan following the independent psychiatrist's diagnosis of a Personality Disorder.

- Working with Risk

5.3.19. The author of the Manx Care report highlighted the view of the Independent Psychiatrist that there had been multiple occasions when Emma did appear to be suffering from:

- mental illness with a defined risk to her health,
- a less-well-defined risk to herself and others,
- aggression towards others
- a lifelong tendency to disengage or decline psychiatric services,
- vulnerability in the community
- long-standing concerns about her ability to engage in community care plans
- Suicidal ideation

5.3.20. The Manx Care author concluded there were missed opportunities to detain Emma under the Mental Health Act to clarify diagnosis and treatments. This view is noted. However, it can be difficult to retrospectively judge the decision making, without understanding all circumstances of the case at the time of those Mental Health Act assessments. Decisions about the necessity and therapeutic value of an admission for a person with a personality disorder may be finely weighed. Dependent upon the type of personality disorder guidance recognises that the person may be best helped by maintaining autonomy and being supported in the community to develop skills to manage crises. However, guidance recognises the fine balance needed as refusal to admit the person may endanger them.[30]

5.3.21. When Emma was detained for inpatient care in January 2020, she was discharged after four days. It was concerning that despite Housing raising concerns about her home environment, there was no evidence of using professional curiosity to explore this further - Emma was discharged before her home conditions could be assessed.

5.3.22. There did not appear to be any comprehensive assessment or risk management plan in relation to self-neglecting behaviours. It is also not clear what work had been done with Emma on developing a safety plan or whether she was able to use any strategies to reduce risks of relapsing back into crisis and the lack of self-care that was part of this. The Crisis Team expressed a view that Emma had been discharged too early – the plans to readmit Emma as an informal patient perhaps supports this view.

5.3.23. There is little information regarding the role of Emma's GP in responding to risks, including risks arising from self-neglect. Emma was prescribed pain killers for her physical health conditions. Guidance highlights the risks of addiction to pain killers, particularly where the patient has a history of trauma and where there is risk of deliberate self-harm.[31] All GPs and Pharmacists in IOM should be reminded of these guidelines relating to the role of drug treatment and drug treatment in crisis for people with personality disorder.

[30] NICE https://www.nice.org.uk/guidance/cg78/evidence/cg78-borderline-personality-disorder-bpd-full-guideline3 [accessed May 2022]
[31] National Institute for Clinical Excellence Borderline personality disorder: recognition and management Clinical guideline [CG78]Published date: 28 January 2009 https://www.nice.org.uk/guidance/cg78/chapter/1-Guidance#general-principles-for-working-with-people-with-borderline-personality-disorder [Accessed May 2022]

5.3.24. Police had taken a major role in responding to welfare concerns about Emma. Records indicate that Police Officers were responsive and made appropriate follow up through MARFs and direct referrals to mental health services – nine referrals during the last two years of Emma's life.

5.3.25. Emma had a history of a contentious/abusive relationship with ex-partner(s). She had talked about an ex-partner moving in and taking her medication, and also feeling persecuted by the partner. In May 2020 she told her Psychiatrist that she had been sexually interfered with two years earlier by her ex-partner. Research highlights the impact that domestic abuse has on mental health including risk of suicide.[32] The psychological damage of domestic abuse also impacts on a person's motivations/ability to care for themselves and their environment.

5.3.26. It is not clear from the records, how well services recognised and responded to Emma's vulnerabilities to Domestic Abuse. A recent IOM SCMR[33] has highlighted the lack of basic infrastructure in IOM to identify and respond to domestic abuse.

5.3.27. Emma had also made many allegations about her property being stolen. Police investigations found no evidence. Emma felt fearful and had periods where she kept a knife under her pillow. It was believed that her beliefs and fears were part of her psychiatric presentation. This may well have been the case but there is a risk of diagnostic over shadowing i.e. where a person's mental illness causes biased judgements about the validity of statements/accusations made or the reasons for behaviours. There is a need to ensure rigour in assessing concerns through the lens of safeguarding making referrals were Safeguarding Adult criteria apply.

- ## Working Across Agencies and Communities

5.3.28. As noted, police did complete MARFS following contacts with Emma. The crisis team had also made a referral to Safeguarding Adults – it is not clear whether this was due to concerns about self-neglect or of other concerns. It is concerning that ASC have no record of this referral and that the lack of response was not escalated by mental health services. An IOMSB independent review in 2020 of Safeguarding Adults made several recommendations to strengthen Safeguarding Adults[34] but there has been limited progress. The systems to support practice is discussed in section 6.

5.3.29. There is substantial research into the challenges of working with people who have personality disorders.[35] Interventions can lead to divisions and conflict between professionals where there is not a shared understanding of the person's needs and care plans.

5.3.30. There was a record of a multi-disciplinary meeting within mental health services but plans for further meetings were not followed through. There were some good examples of collaboration between police

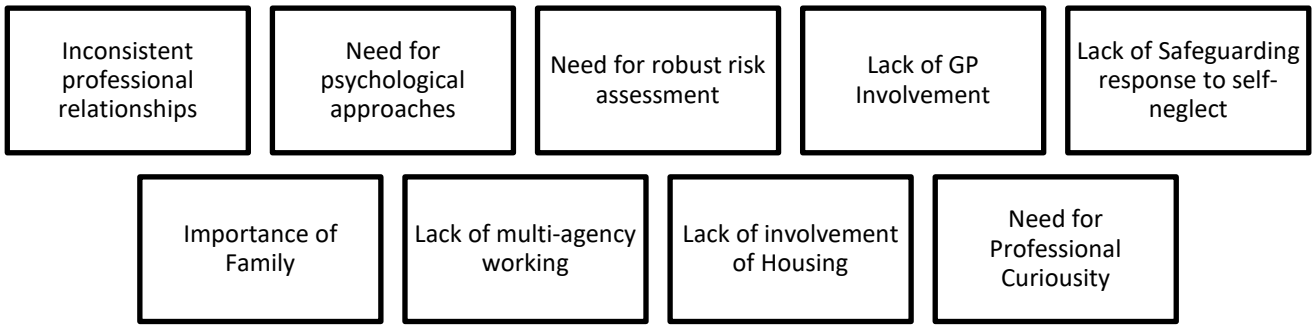
[32] Professor Sylvia Walby 'The Cost of Domestic Violence', London: Women and Equality Unit, 2004 https://www.lancaster.ac.uk/fass/resources/sociology-online-papers/papers/walby-costdomesticviolence.pdf [Accessed June 2022]
[33] IOMSB SCMR 'Family K' 2022
[34] Isle of Man Safeguarding Board Review of Multi-agency Safeguarding Adults Arrangements, Interim Report 2020; Available through IOMSB [Accessed May 2022]
[35] British Journal Medical practitioners Current healthcare challenges in treating the borderline personality disorder "epidemic 2018;11(2):a1112 https://www.bjmp.org/files/2018-11-2/bjmp-2018-11-2-a1112.pdf [Accessed December 2020]

and mental health services, for example joint visits in response to crisis. Whilst this was good practice, this could have been built on by developing a shared crisis response plan with Emma and seeking her consent to share with police and other key agencies involved at point of crisis.

5.3.31. As noted, there was very limited evidence of any joint work with Emma's GP – one contact in the month she died. Housing had had some involvement due to the concerns about damage to Emma's tenancy and responses to complaints and concerns from neighbours. However, there is no sense of any partnership working with Housing in Emma's ongoing care planning. This may reflect a wider lack of involvement of Housing providers in care and support, including working with self-neglect. An earlier SCMR[36], highlighted gaps in Social Housing policy for tenants with vulnerabilities and recommended Housing related support.

Recommendation Arising

Emma: Summary of Learning Themes



5.4. Thomas: Background and Key Events

5.4.1. Thomas was in his thirties when he died in **June 2020**. The cause of his death was an overdose of Venlafaxine whilst under the influence of alcohol. It is not clear whether he intended to die. At the time of his death, Thomas was neglecting his self-care, with very poor and unhygienic conditions in his home.

5.4.2. Thomas lived alone having separated from his wife although his wife remained a key support for him. He had a long history of anxiety and depression. Thomas also had problematic substance and alcohol use. He was well known to mental health services, the Drug and Alcohol Team (DAT) and his GP. Thomas had periods of successfully controlling his alcohol use but also recurrent relapses. At times of relapse, Thomas could behave impulsively, with acts of deliberate self-harm and suicidal thoughts and attempts.

5.4.3. At times, Thomas self-referred to police when in mental health crisis. Police were also contacted at times by Thomas's ex-wife, requesting welfare checks. In **early 2020,** Thomas was working with DAT with his keyworker and psychiatrist. He appeared to be stable and doing well.

5.4.4. In **May 2020**, Thomas had a phone consultation with his psychiatrist. He remained stable and the psychiatrist had plans to discharge him if he continued to be settled. Very sadly, six weeks later, Thomas took an over-dose while intoxicated and died.

[36] The Isle of Man Safeguarding Board The Learning from a Serious Case Management Review in respect of Mr H Independent Author: Domini Gunn-Peim Published May 2020

Thomas: Learning Themes

5.4.5. Thomas' impulsive self-harm and periods of self-neglect appeared to be a directly attributable to his relapse in alcohol use. Alcohol Change UK[37] highlighted the need for early intervention before chronic dependency on alcohol is established with alcohol screening, advice and referral onto specialist services. People who may be resistant to change can be helped through assertive outreach approaches and a structured/coordinated multi-agency approach. Alcohol UK highlighted the high rates of co-existent depression (60- 70%), poor sleep and poor nutrition. The guidance also referenced the psychological barriers that people may face. Building motivation and self-belief can be challenging. There is a double bind of using alcohol to blot out past emotional traumas but drinking causing further suffering.

5.4.6. Thomas was engaged with specialist services and received multi-disciplinary input. Thomas responded well to mental health services but could not always sustain engagement. The cycle of behavioural change is well established in alcohol and substance misuse services. This plots the different stages of motivation in addressing problematic substance use[38]and recognises that progress is unlikely to be straight trajectory.

5.4.7. There is evidence of mental health services and DAT being responsive to Thomas – using opportunities when he was more motivated to address his alcohol use. Services attempted to understand the triggers and stressors for his relapse and his self-harm, although the records did not give any background history or identify potential reasons for drinking or self-harm.

5.4.8. There is good evidence of police responsiveness and sensitivity toward Thomas. Police also engaged with Thomas' ex-wife when she raised welfare concerns, enlisting her to support Thomas at Emergency Department when police had conveyed him there during a crisis. Police followed these episodes up by submitting an adult MARF.

5.4.9. Prior to his death, there were no concerns that indicated a need for a safeguarding response. Thomas' alcohol use was the primary focus and this was being appropriately addressed through the DAT, working with mental health services and Thomas' GP, supported by police at points of crisis.

5.4.10. Thomas lived in private accommodation. It is not known whether he was a homeowner or was in private rental. It is also not known whether he had any difficulty sustaining his accommodation. People with alcohol dependency can often have problems sustaining a tenancy, and be at higher risk of eviction. Overcoming addiction becomes all the more difficult for people who are homeless.[39] The Housing sector across the UK are commissioned to provide specialist housing support for people with a range of vulnerabilities including mental health problems and drug or alcohol problems. There is national

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[37] Alcohol Change Uk Blue Light Project https://alcoholchange.org.uk/help-and-support/get-help-now/for-practitioners/blue-light-training/the-blue-light-project [Accessed June 2022]
[38] World Health Organisation (2003) Intervention for Substance Use: Brief Intervention for Substance Use: a Manual for Use in Primary Care -Draft https://www.who.int/substance_abuse/activities/en/Draft_Brief_Intervention_for_Substance_Use.pdf [Accessed May 2022]
[39] The Housing Needs and Experiences of Homeless Drug and Alcohol Users in Stoke-on-Trent Sheffield Hallam University 2009 file:///C:/Users/sylma/Downloads/housing-needs-exp-drug-alcohol-stoke.pdf [Accessed June 2022]

guidance to support this work.[40] This provides an essential network of support but is under-developed in the IOM.

Recommendation Arising

Thomas: Summary of Learning Themes

Correlation alcohol and self-neglect	Need for Housing support [TBC]	Importance of Family

5.5. James: Background and Key Events

5.5.1. James was a man of White British heritage who was in his sixties when he died. The primary cause of death was Myocardial Ischemia, secondary diagnosis liver cancer. At the time of James' death, he was very poorly nourished. His house was in very poor state of repair and he had been sleeping with no sheets on a blackened bed.

5.5.2. James had a daughter who remained in the UK. She had monthly phone contact with him. James' daughter and one of his friends provided some background information about him.

5.5.3. In the past, James had owned a hotel in the UK which he ran with his wife before they separated. James had struggled with mental illness since his teenage years. Records indicate he was diagnosed with bi-polar affective disorder in 2000, although his family note he was diagnosed in the UK in 1987.

5.5.4. James' daughter recalled that James would have long periods where he would shut himself away. James moved to the IOM nearly twenty years ago and used all his money to buy a house that was near derelict. He had little spare money. Over the years, he became more financially stable but chose not to spend his money.

5.5.5 James' friend recalls that in the past, James had been smart in his appearance and managed everything well. She recalled that he loved his dogs and was devasted when they died. He stopped going out. His friend recognised that James could struggle if there were '*any bumps in the road*' and had period when he would just stop answering the phone. James' daughter also experienced these periods when she would lose any contact with her father but understood he would come out of his seclusion in time.

5.5.6. James had very limited contact with his GP. He had been prescribed sleeping medication (Zopiclone) for 20 years. Up until the year before he died, James had not had any involvement from mental health services.

5.5.7. In **October 2020**, James attended his GP. He appeared dishevelled, flustered and distressed. He declined any support other than sleeping medication. The GP noted James had capacity to decline any other

[40] Local Government Association Specialised supported housing: guidance for local government and NHS commissioners 2020 https://www.local.gov.uk/publications/specialised-supported-housing-guidance-local-government-and-nhs-commissioners [Accessed June 2022]

support. The GP stopped his medication and referred him to the mental health Crisis Team. The Crisis Team made a home visit. James had some symptoms of illness but did not want any further support. Three days later, Police found James in a confused state. He was admitted to general hospital for checks. James' daughter contacted the hospital and provided background about his mental health. James was admitted for mental health inpatient care.

5.5.8. James was very thought disordered and had poor self-care. He was fixated on spending large sums of money. His daughter had been concerned about risk of over-spending and of financial exploitation. The bank had contacted her concerned about James' presentation and in discussion with her, had frozen his financial assets.

5.5.9. James was discharged from hospital in **November 2020** with follow up support from the Older Adults Mental Health Service (OAMHS). He was discharged from that service in **March 2021** at his request.

5.5.10. Sadly, James was found to have died at home in **September 2021**. His neighbour had contacted the police after not seeing him for a few days.

James: Learning Themes

- Engagement

5.5.11. James had had life-long struggles with his mental health and yet until the last year of his life, had very limited support from agencies. People with stable mental illness can be well supported within Primary Care, without needing involvement from secondary mental health services. However, it seemed that James was lost from sight. He had very little contact with his GP though had been prescribed sleeping medication for nearly twenty years. Treatment guidance for bi-polar disorder recommends a review of treatment and care, including medication, at least annually and more often if the person, carer or healthcare professional has any concerns. Guidance is also to offer evidence based psychological interventions.[41]

5.5.12. There is no evidence these guidelines were followed. Although James had very little contact, it appears there was no system to flag his vulnerabilities associated with his bipolar illness; no professional curiosity about his lack of contact and the need to make more assertive outreach to review his care. It was not until he was reviewed by a Locum GP in 2020, that there was a proactive response to pause his medication and seek review by mental health services.

5.5.13. James' daughter confirmed that James felt he did not need any services. He had always backed away from any discussion about his mental illness – it had been a taboo subject within their family. James' daughter's view was that her father was good at avoiding services and that mental health services had done as much as they could to keep involved. She described his mental health hospital care as good as was the follow up from OAMHS – both services kept her involved and informed. James' friend confirmed that he liked members of the OAMHS but didn't want them to keep calling.

[41] National Institute for Health and Care and Excellence Bipolar disorder: assessment and management Clinical guideline [CG185]Published: 24 September 2014 Last updated: 11 February 2020 https://www.nice.org.uk/Guidance/cg185 [Accessed June 2022]

5.5.14. The OAMHS tried different ways to sustain engagement but ultimately, James' decided to end involvement. His daughter recalls the OAMHS contacting her to let her know they were ending involvement and passing on contact details if concerned.

- Working with Risk

5.5.15. James had the right to end involvement. There were no concerns about his capacity, his mental health was stable and there were no grounds for compulsory treatment. Mental Health services did develop a relapse prevention plan with him. James' daughter had also asked services to provide them with information about his illness and signs of relapse. She found this very helpful in being able to open up conversations with her father for the first time – the materials had helped her to get over the taboo of talking to him about his mental health.

5.5.16. There was good practice in managing risks around James' over spending and risk of financial exploitation. The IOM Bank identified concerns about James' mental health and alerted his daughter. The bank also kept her in touch during James' admission when inpatient staff were trying to help him access accounts.

5.5.17. It is not clear from records how well risks associated with self-neglect had been specifically assessed. There are no records to indicate home based assessments, prior to James' discharge and no assessments by Occupational Therapy post discharge. It may be that his CMHP had been able to carry out home based assessments. Given the concerns about James' self-care at point of admission, this should have been clearly referenced within a risk assessment and management plan. James died six months after OAMHS ended their involvement and at that point he was in poor physical condition and his home was in very bad repair. There is no benchmark to judge whether his self-care and home environment had deteriorated quickly over this period, or whether these concerns had been apparent at point of closure.

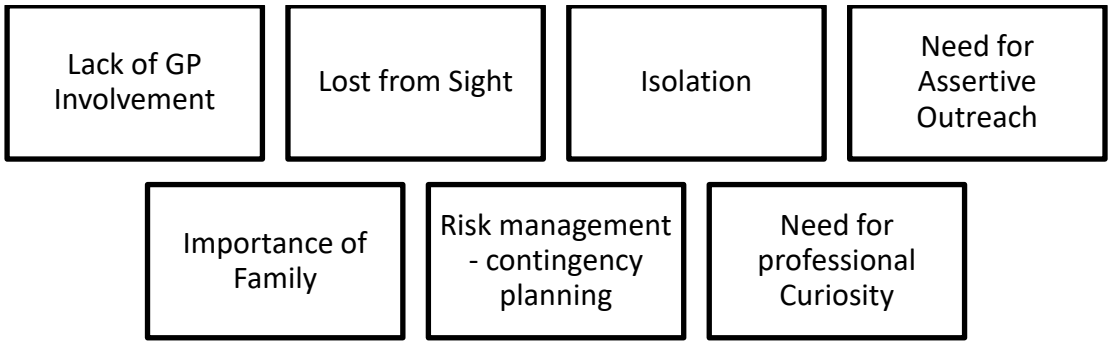
- Working Across Agencies and Communities

5.5.19. James' had lived a relatively isolated life. When he ended involvement with OAMHS, there was a limited safety net of supports that could escalate concerns about a relapse. As noted, there was good communication between mental health services and James' daughter, but she did not live in the IOM.

5.5.20. There was limited communication between mental health services and James' GP practice. There are no records of liaison between those services prior to James' discharge from hospital. OAMHS did write to inform James' GP that they were ending involvement. However, it is not clear how that discharge planning was coordinated within the GP Practice i.e. additional steps to keep him engaged; understanding of relapse indicators and a contingency plan. There is a need for agencies to consider how they can come together to provide a 'Team Around the Adult' network of support. Primary Care can play in central role in this.

Recommendation Arising

James: Summary of Learning Themes



5.6. Margaret: Background and Key Events

5.6.1. Margaret was a woman in her eighties when she died in **March 2021.** She died of hypothermia following a fall in her unheated house. Margaret was not registered with a GP and was not known to any other services.

5.6.2. Margaret originated from a European Country and had come to live in the IOM many years ago. Margaret's neighbour (and friend) described her as a very private and independent person. She lived alone having separated from her husband. Margaret was believed to be financially secure. She enjoyed fine furniture, paintings, and fashion. Margaret had been an accomplished artist and enjoyed the company of other artists.

5.6.3. Margaret's life changed approximately four years before she died. Margaret sustained a hip injury following a fall outside her house. Margaret stopped being able to drive and the standards in her home began to deteriorate. Her neighbour believes that Margaret became embarrassed about this and so stopped contact with her friends. She gradually became more isolated.

5.6.4. Her neighbour had known Margaret for many years, and had phone contact most days. He seemed to be one of the few people Margaret would allow into her home. He recalled she never put the heating on. Over time, her neighbour noted deterioration in the hygiene standards of the house. At one point, Margaret asked her neighbour to help find a cleaner. However, she then declined to let the cleaner into the house, saying she would rather clean up a bit first.

5.6.5. Margaret's ex-husband had engaged his IOM financial investment manager to visit Margaret to try and help. She declined to let them in. Her neighbour believes this investment manager arranged for a care agency and tried to get an alarm pendant in place, but Margaret declined. The investment manager asked the neighbour to '*keep an eye'* on Margaret.

5.6.6. Latterly, her neighbour noted Margaret had become very thin – her diet being very limited. She used to tell her neighbour that she wanted nothing to do with social services. He believed that she was well able to make decisions for herself, her only impairment being her physical mobility.

5.6.7. Margaret's death was discovered by the police who had been alerted by her neighbour, having not seen her for a few days. The Coroner '*did not find that failings on the part of any person or body contributed to their deaths but do consider that …..fell through the net of support that might have been available.*'

Margaret: Learning Themes

5.6.8. Margaret's world seemed to close in following her fall. There are no records of Margaret attending for any treatment following her fall. Had services known of Margaret's injury, potentially the combination of acute care and rehabilitative physio and occupational therapies could have limited the impact and maintained her independence and wellbeing.

5.6.9 It is not clear why Margaret was so resistant to having any external involvement from agencies. Sadly, no professional got close enough to understand her motivation. It is difficult to see how the network of support that the coroner referred to, could have been mobilised for Margaret as she was out of sight of any agency.

5.6.10 Her neighbour was one of the few people in Margaret's life that had any contact. She appeared to value his support. The neighbour appeared to be compassionate and respectful, recognising her loss of dignity. His view was that even had agencies known about her circumstances, Margaret would have resisted any offers of help and that there was little that services could have done.

5.6.11. Margaret's circumstances demonstrate the key role that neighbours, and local communities can play in supporting people who may be isolated, not known to agencies and resistant to involvement from others. There is potential for friends and neighbours to provide a catalyst to linking into agency support. However, the public are often not aware of what role service can offer in relation to self-neglect.

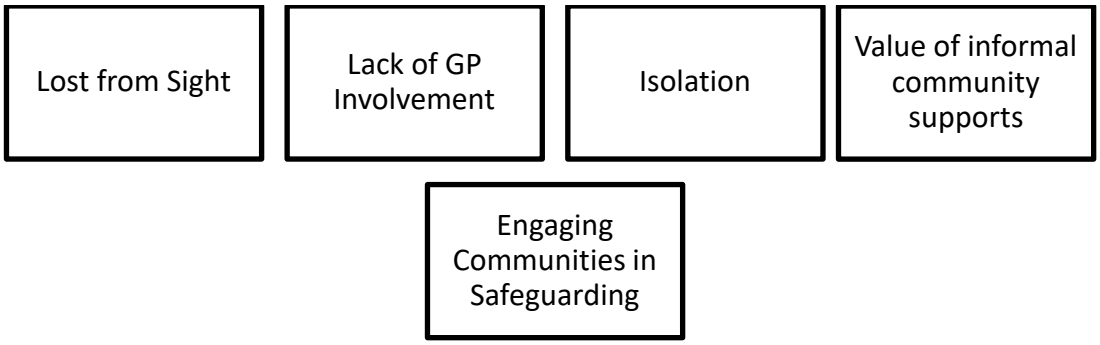
5.6.12. A review of Safeguarding Adult in 2020,[42] highlighted that there is a low level of public awareness and community engagement in Safeguarding Adults work. Margaret's neighbour had no knowledge of what 'Safeguarding Adults' was or who he would contact if he was concerned about someone was being abused or neglected. He felt that he would not have been able to go against Margaret's wishes.

5.6.13. Margaret's ex-husbands financial advisor was also clearly trying to find ways to help her. The lack of any contact with ASC does seem to reinforce a lack of public awareness within the IOM about supports available for people who may be self-neglecting.

5.6.14. Margaret was lost from sight of agencies. Sadly, this precluded any opportunities for agencies to try and engage her, assess risks or coordinate multi-agency support for her.

[42] Isle of Man Safeguarding Board Review of Multi-agency Safeguarding Adults Arrangements, Interim Report 2020; Available through IOMSB [Accessed May 2022]

Margaret: Summary of Learning Themes



5.7. Harriet: Background and Key Events

5.7.1. Harriet was a Manx woman who was in her seventies when she died of hypothermia. Her house was in very poor condition. A window had fallen out and there was hole in the roof. There was no heating or food in the house. There was clutter and rubbish everywhere. The house was full of thick, matted cobweb and there was no working toilet, shower or bath within the property. Harriet had been sleeping on a very small corner of a dirty bed that was predominantly covered with rubbish and household items.

5.7.2. At the time of her death, no agencies were involved with Harriet. Harriet had received repeat prescriptions but had had no direct contact with her GP. Agencies knew very little about her but a friend who had known her from childhood was able to provide some information about her.

5.7.3. Harriet lived in her own house. She had a reclusive lifestyle with no known contact with her family or others apart from her friend. Harriet's friend described her as a very kind, tender and intelligent person. Harriet had attended university. She was an artist and played piano very well. She was a 'great collective of things' particularly piano keyboards, and her house was crowded with belongings.

5.7.4. A friend of Harriet's had contacted Police in **November 2017,** concerned about Harriet's welfare. Police visited and were concerned about her home conditions so made a MARF referencing '*very dusty, damp and messy…clear evidence of hoarding, making it very difficult to move around the property and, in the Officer's opinion, not fit to be lived in*.' There is no record of what followed this referral.

5.7.5. The last time Harriet's friend visited her was on her birthday, but Harriet didn't want to let her in. Her friend thought this was because she would be too embarrassed about not coping and not wanting to trouble anyone.

5.7.6. Harriet's death was discovered in **December 2020** when police responded to a call from a member of the public. The person narrowly missed being hit on the head by a skylight that had fallen off her property. The Coroner did not find any failing on any person or agency but did highlight that Harriet '*…fell through the net of support that might have been available*.'

Harriet: Learning Themes

5.7.7. Harriet's friend said she was very closed toward people she didn't know. Harriet wanted to keep her problems to herself and fought very hard to be independent. It is not clear the reasons why Harriet

became reclusive. Her friend referenced her mother dying when she was young, and a difficult relationship with her stepmother.

5.7.8. Harriet had been on repeat prescriptions but had not been seen. It is not clear whether the extent of her health needs would have merited the GP Practice nominating a Named GP and/or having a system for reviews such as annual health checks. Potentially, a holistic review could have identified concerns about her self-neglect and hoarding behaviours although Harriet was adept at keeping her difficulties hidden.

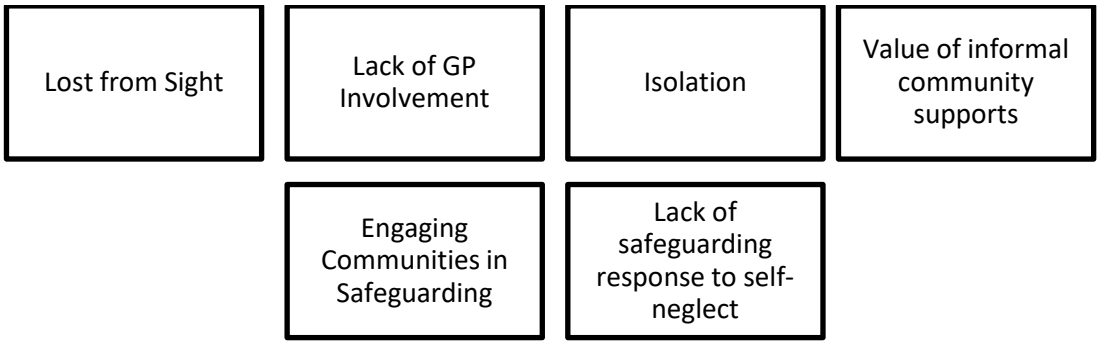
5.7.9. There was a brief record from 2017 of ASC offering support to Harriet. It is not clear whether this involvement was triggered by her GP - the record does reference the GP had concerns about her bone density and potential arthritis. The record provides no detail to indicate eligibility or reason for the need for support. There is no reference to concerns of self-neglect and no record of what Harriet's response to the contact was.

5.7.10. Harriet's friend had not known the extent of Harriet's problems. Her friend was not aware of what Safeguarding Adults was or how to raise concerns.

5.7.11. The occasion, in November 2017, when a friend did raise concerns through the police, was a significant missed opportunity. Police appropriately raised a MARF. It is very concerning that there is no record of that MARF – it is not clear if it was received, and if it was, what the rationale was for any decisions made regarding assessment and responses to self-neglect. There is no evidence of any follow up response. This reinforces findings from an Independent Review of IOM Safeguarding Adults, that highlighted a concerning lack of any robust Safeguarding Adult pathway for self-neglect.[43]

Recommendation Arising

Harriet: Summary of Learning Themes



[43] Ibid

6. Strategic Responses to Self-Neglect

6.1. The stories of the seven people who are subject to the review identified a number of themes:

Engagement	➢ Risks where people are isolated and out of sight. ➢ The need to raise public awareness of safeguarding responses to self-neglect ➢ Time and support needed to develop consistent and purposeful relationships ➢ The need for professional curiosity ➢ The value of assertive outreach approaches ➢ A need to improve access for psychological/mental health assessment ➢ A need to develop psychological approaches and resources, to understand behaviours and provide therapeautic responses
Working with risk	➢ Risks of desensitisation by practitioners working with self-neglect ➢ The need to strengthen risk assessment and risk management, incorporating principles of wellbeing and Making Safeguarding Personal ➢ The importance of legal literacy - understanding what legislation may apply including formal assessment of mental capacity where indicated.
Working Across Agencies and Communities	➢ The key role of family and friends and the need to involve them in partnership responses ➢ The value of wider communities in building informal network of support – 'Team Around the Adult' ➢ Appreciating the value of Primary Care as a safety net and the need to ensure GP's are engaged in responses to self-neglect ➢ The need to develop Housing support and involve in partnership working ➢ Lack of multi-agency responses ➢ Lack of Safeguarding Adult responses to self-neglect

6.2. Research identified key strategic factors required to support practice.[44]

[44] Social Care Institute for Excellence, Braye., S, Orr, D., and Preston-Shoot, M., (2015), *Self-neglect Policy and Practice: Research Messages for Managers*, Available from: https://www.scie.org.uk [Accessed January 2022]

6.3. The learning from the review of the seven people indicate systemic barriers to effective practice.

6.4. It is striking that there was no use of Self Neglect guidance in any of the seven cases and none resulted in a Safeguarding Adult Enquiry. This is not just about individual practitioners failing to follow procedures. There is a need to understand why this was so wide spread.

6.5. In some cases, there was a lack of identfying the person's behaviours as self-neglecting. In other cases, self-neglect was identified but then not connected to being a safeguarding matter. There had been no training on self-neglect. Contributors also talked about a generally accepted view that the self-neglect policy was not fit for purpose. The policy when launched, had been supported by the IOMSB and by managers. However, over time, and with changes in management this drifted. The policy now appeared to be operating in a vaccum without the training, resources or commitment from leaders to support it. One example was the self-neglect panel. This was set up to guide practitioners but faltered without any ownership or leadership.

6.6. There appeared to be lack of policy direction or clear pathway about when self-neglect should be responded to as a Safeguarding Adult Enquiry or when responses can be made through other multi-agency mechanism. Multi-agency working should be core to each worker's practice and each worker is accountable for ensuring effective information sharing. There were no alternative multi-agency structures designed to respond to self-neglect. Although any practitioner could have called a meeting, none did.

6.7. The Independent Review of Safeguarding Adults highlighted a concerning lack of leadership and accountability for Safeguarding within ASC and for self-neglect.[45] This meant there was a lack of rigour and accountability in managing risks, and a lack of supervision to support practitioners, including prompting the need for professional curiousity and providing critical reflection on areas such as compassion fatigue and desensitisation.

6.8. Lack of leadership also meant that gaps in resourcing were not addressed.The review learning event heard that practitioners were constrained by time. This limited the ability to apply assertive outreach techniques that go beyond the transactional task focused approach, that standard practice may allow.

6.9. The restrictions resulting from the Covid Pandemic was noted in some, but not all the cases. For people such as Robin, the restrictions limited contact by key people in his life such as his befriender. However, the Covid Pandemic did not appear to be a significant factor in the learning themes about responses from agencies. There was no substantive changes to the way that practitioners had been responding to self-neglect.

6.10 The review of the seven people, did highlight those who were isolated and lost from sight, including from their GP. This raises bigger questions about how well GP Practices identify patients in vulnerable circumstances and what network of support can be offered at Primary Care level. Contributors commented on a culture of not involving GP's in safeguarding and of recurring blocks to sharing

[45] Ibid

information. A recommendation relating to this has been made in another SCMR.[46] The IOMSB has also recently developed information sharing guidance to assist in this.[47]

6.11. Practitioners talked about the lack of resources to support their work with people who self-neglect. One example was access to psychological resources for assessment and therapies. Practitioners also need to be able to apply for a financial waver for exceptional circumstances where risks from self-neglect are due to resistance to paying for services.

6.12. Improving responses to self-neglect is not just a matter for IOM's Health and Social Care Directorate. Currently there is a notable lack of any coordinated strategic approach to self-neglect across IOM Directorates. There is a need to understand what resources there are in local communities and how those resources can be mobilised to respond to self neglect. Gaps in Housing support also featured in the learning and reinforced learning from an earlier SCMR.[48] There is a need to develop Housing Support provision within the Housing sector and/or through developing third sector provision.

6.13. There is a need for a IOM self-neglect strategy that sets out how the IOM Departments will work together to develop responses to self-neglect - building a network of support across services and communities.

Recommendation Arising

6.14. This is a substantial agenda but there are also opportunities. The IOMSB has recognised the risks and is prioritising improvements in self-neglect. There is a working group to update the Safeguarding Adult procedures and the self neglect procedures. While it is positive that some progress has been made, there does need to be caution that these changes are not made in a vaccum. Procedures need to be written to reflect agreed pathways and reference resources that are available.

6.15. Manx Care has new leadership and is focusing on strengthening Safeguarding Adults across Health and Social Care – management accountability for standards of practice, developing operational guidance and risk assessment tools, and embedding Safeguarding in day-to-day practice. There have been new Designated Safeguarding Adult posts within Health, providing leadership and developing systems to improve responses by health services.

6.16. Manx Care is planning to establish a multi-agency safeguarding hub (MASH) that will improve the response to Safeguarding Adult referrals – collating information across partners and improving the multi-agency decision making. At time of the review, there was a business case to approve funding for additional specialist posts to support the MASH. There were also plans to establish a Vulnerable Adults Risk Management Panel.

6.17. Manx Care had also broadened the remit of their Adult Generic Social Work team. Pracititoners are given the time to engage, and the flexibility to work creatively with adults who are self-neglecting.

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[46] IOMSB SCMR 'Family K' 2022

[47] Isle of Man Safeguarding Board Information sharing guidance for professionals working with children and adults at risk of abuse or neglect. https://www.safeguardingboard.im/media/kxujdg0h/20220201-final-information-sharing-guidance.pdf [Accessed May 2022]

[48] The Isle of Man Safeguarding Board The Learning from a Serious Case Management Review in respect of Mr H Independent Author: Domini Gunn-Peim Published May 2020

6.18. Manx Care is also developing Wellbeing Partnership Hubs across the IOM. These Wellbeing Partnerships, cluster agencies together to coordinate care. There are new roles of Local Area Coordinators that help to reach out to people and connect them to services and communities.

6.19. The Wellbeing Hubs provide great potential to offer a 'Team Around the Adult' approach to supporting people with more complex care needs including self-neglect. Any practitioner can refer into the Wellbeing Partnership Hub. Their meetings provide the mechanism to bring all the potential players together in a coordinated, solution focused way. The Wellbeing Partnership Hubs could be a core part of the pathway in responses to self-neglect but this will need to be formalised and supported through the leadership of strategic partners.

6.20. The Department of Infrastructure (DOI) Housing, contributed to the review and confirmed their intent to develop their Housing Support offering as a potential intervention across the sector. Doing so will require political support, funding and ultimately appropraitely trained resource, however would provide a natural link to the LAC work as part of their longer term Housing Strategy. The imminent implementation of the Mental Capacity Act also offers the DOI Local Government Team and Legislation an opportunity to collaborate with the IOMSB to ensure agencies provide training and guidance and that the Act is embedded in practice. This is also an opportunity to engage the public and communities in understanding Safeguarding Adults and the relevance of the Mental Capacity Act to this.

6.21. These initiatives are welcomed. There is the opportunity to bring these strands together through a IOM self-neglect strategy, to address many of the learning points raised within this review.

Recommendation Arising

7. Conclusions

7.1. This review has considered the very sad circumstances surrounding the deaths of seven people. The review has highlighted the care and compassion shown by members of the community and has also given many examples of good practice by committed practitioners.

7.2. The review has highlighted the risks where people are lost from sight. It has demonstrated the challenges in supporting people who are resistant to receiving any help. It has also highlighted some recurring concerns regarding practitioners becoming desensitised and working in the absence of robust risk assessments. Recurring themes included the lack of professional curiosity about people's lack of engagement and home circumstances. There was a lack of appropriate assertive outreach and the failure to follow multi-agency procedures.

7.3. The learning themes reveal significant gaps in the strategic systems that should support frontline practice. Addressing those gaps must be coordinated through a comprehensive cross-departmental strategy if the IOM is going to reduce the risks of people dying in such sad circumstances of self-neglect.

8. Recommendations

The following recommendation take account of individual agencies own recommendations and improvements recently made.

Recommendation 1

The IOMSB, on behalf of the IOM Government, should lead a strategy and implementation plan for self-neglect, with sign up by the relevant IOM Government Departments. The strategy and implementation plan should deliver:

1.1. Pathway	A pathway for a 'Team Around the Adult' approach to self-neglect
	• Building support around Primary Care:
	  ○ Policies/quality assurance on use of repeat prescriptions
	  ○ Regular review of vulnerable patients
	  ○ Systems to flag patients with vulnerabilities who are 'lost from sight'
	• Role of communities and families
	• Role of Wellbeing Partnership Hubs
	• Role of Safeguarding Adult Enquiries
	• Robust Information sharing across the pathway

1.2. Policy and Procedures	Policy, procedure and guidance detailing application of the pathway • Working with self-neglect and Making Safeguarding Personal • Guidance on risk assessment and risk management • Guidance on legal framework • Cross referenced to related policy e.g. information sharing guidance; financial waver protocol • Quality standards and managerial accountability
1.3. Training and Supervision	• Competence framework and training plan for self-neglect • Training in mental capacity • Agency standards for supervision
1.4. Resources	• Housing strategy to support tennants with additional needs including adults who may self-neglect • Access to mental health/psychology assessments and treatments (including assertive outreach approaches) • Case load weighting to enable additional time/assertive outreach for self-neglect • Provision of advocacy • Mapping and gaps analysis of third sector provision • Development of a multi-agency, solution focused panel to support practitioners
1.5. Involvement of Families and Communities	• Development of Family Group Conference within the self-neglect pathway • Campaign to raise public awareness to self-neglect and Safeguarding Adults and mobilise support within communities

Recommendation 2

Manx Care mental health services should develop a policy to guide practice where service users do not attend appointments. The policy should include guidance on risk assessment, proportionate and reasonable measures for follow up, including communications with other agencies and family as appropriate.

Sylvia Manson,

Date: August 2022

Glossary

ASC Adult Social Care

CSS Community Support Service

CMHP Community Mental Health Professional

CMHS Community Mental Health Services

DN District Nurse

IOMSB Isle of Man Safeguarding Board

MASH Multi-Agency Safeguarding Hub

OPCSWT Older peoples Community Social Work Team

OT Occupational Therapist

SCMR Serious Case Management Review

SW Social Worker

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