Investigating deaths of people with autistic spectrum disorder in health and social care in England and Wales

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Abstract

Purpose – *This paper aims to examine the trends identified in inquests conducted in the Coronial system in England and Wales for individuals formally diagnosed with autism spectrum disorder (ASD), where the death occurred within a health or social care setting.*

Design/methodology/approach – *It uses data from 42 reports to prevent future deaths (PFDs) issued by Coroners to establish where and in what contexts each death occurred. PFDs are sent to organisations that Coroners believe could act to PFDs.*

Findings – *The research identified four key findings. Firstly, 33% of the deaths identified were not recorded as suicides, marking a clear departure from the extant literature on this issue. Secondly, data highlighted a lack of training and education of staff to understand the complexity of autism. Thirdly, this lack of understanding was often compounded by a lack of specialist provision for people with ASD. Fourthly, Coroners attributed a number of deaths to an individual's autism, which served to some extent to mask the failures of the agencies involved in the care of the decedent.*

Originality/value – *There is limited research available about the preventable deaths of individuals with ASD in health and social care settings. This paper makes an initial step in highlighting significant structural failures that can lead to preventable deaths.*

Keywords *Autism, ASD, Preventable death, Suicide, Coroners*

Paper type *Research paper*

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Data availability statement: The data that support the findings of this article are available upon reasonable request from the corresponding author.

Ethical approval: The project uses data in the public domain, as such no ethical approval was sought.

Context

There is widespread consensus about the lack of accurate data regarding deaths of people with autism spectrum disorder (ASD) in England and Wales, a lack of standardised reporting mechanisms of deaths of people with ASD and consequently a lack of understanding about how deaths of people with ASD occur (Glover *et al.*, 2017; Heslop *et al.*, 2020; O'Leary *et al.*, 2018; Robertson *et al.*, 2021). This article represents an early attempt to understand how and why deaths of people with ASD occur, by using data generated by Coroners into deaths of people with ASD in health and social care in England and Wales in the period 2017–2023. The article does not focus on all deaths linked to ASD during the period 2017–2023, but focuses on publicly available prevent future deaths (PFDs) where the deceased was formally diagnosed with ASD and their death in a health or social care setting was deemed preventable by a Coroner.

The state owes a duty of care to people and is obliged to uphold their right to life under Article 2 of the European Convention on Human Rights (ECHR). If deaths occur that are unnatural, suspicious or have occurred in the care of the state, then they should be independently and rigorously investigated to ensure the death could not have been prevented (Baker *et al.*, 2023). In England and Wales, Coroners fulfil the statutory

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requirement to uphold Article 2 of the ECHR. It is, therefore, not unusual for them to investigate deaths of people with ASD in inquests.

Inquests into deaths of people with ASD are typically heard before juries in public and consider a variety of evidence relating to the death of that person. At the end of the inquest, a conclusion is reached about how the deceased came to meet their death. The scope of an inquest means that a wide range of structural and organisational factors could be considered causal in relation to the death (Dorries, 2014). The conclusion can include a significant amount of detail about how the death of that person might have been avoided and often relates to organisational actions and/or omissions (Baker *et al.*, 2023). If this is the case, Coroners have an obligation to complete a PFD and send it to any organisation they believe could amend their policy, practice or training in respect of the death of an individual (Dorries, 2014). By using PFD data, the authors are able to contribute important and original knowledge to the issue of preventable deaths and people with ASD within health and social care settings in England and Wales.

In policy and research terms, deaths of people with ASD have typically been considered under the same category as learning disability (LD) deaths. There have been widespread concerns about these deaths for some time, principally from an equality perspective, as highlighted by Mencap's "Death by Indifference" reports published in 2007 and 2012. The latter levelled the charge of "institutional discrimination" (Mencap, 2012, p. 1) at health and social care providers towards people with ASD and LD. The Equality Act 2010 sets out explicit requirements that all public services should deliver equal provision of services for UK citizens. Responding to the charge of institutional discrimination, the government initiated the Confidential Inquiry into Premature deaths of people with Learning Disabilities (CIPOLD) (Heslop *et al.*, 2013). The principal policy outcome of this inquiry was to instigate an annual reporting mechanism focused on the deaths of people with LD funded by NHS England and NHS Improvement. "Learning from Lives and Deaths - people with a learning disability and autistic people" (LeDeR) first reported in 2017. LeDeR produces an annual report about deaths of people with ASD and/or LD who die in England (LeDeR, 2023).

In 2021, LeDeR set out a programme that aimed to learn lessons from LD deaths and build a more rigorous and responsive reporting structure to investigate and understand how such deaths occur (LeDeR, 2021, p. 10). A significant caveat to this is their acknowledgement that there would be no mandatory requirement for organisations to report deaths. The voluntary nature of reporting these deaths means that the data generated is best characterised as being opaque and uncertain. It was not until 2022 that LeDeR gathered disaggregated data on people with a diagnosis of ASD, highlighting the lack of focus from both service providers and regulatory agencies on these deaths.

There is limited academic research on preventable deaths and people with ASD. What there is focuses on suicide; with the great majority of extant literature being of a quantitative and clinical nature. Early studies noted the paucity of available research on this issue (Cassidy *et al.*, 2014; Richa *et al.*, 2014) and this remains the case today (Horowitz *et al.*, 2018; Schwartzman *et al.*, 2023). In addition, authors note a dearth of research into how an individual's position on the autistic spectrum might relate to different types of suicidal ideation/behaviours as ASD is heterogenous (Hochard *et al.*, 2020; Smith *et al.*, 2023).

Common findings are that the suicide risk is greater for individuals with ASD than for neurotypical individuals; and that when comorbidities (for example, depression) are considered, the risk level is further elevated (Hedley *et al.*, 2017; National Child Mortality Database [NCMD], 2024). An NCMD (2024) report into 77 deaths of children aged 4–17 with ASD states that delays in autism diagnoses can increase the risk of suicide, and that the negative impact of these delays on individuals sometimes receives insufficient consideration by agencies. Research has also found the rate of suicidal ideation and

behaviours to be more prevalent in people with ASD than those who have diagnoses of severe mental health conditions (Cassidy *et al.*, 2014; Eyuboglu *et al.*, 2023).

ASD often exists alongside other learning difficulties such as ADHD, in addition to mental health diagnoses. There are evident co-morbidities with diagnoses of both LD and mental health, underlining the complexity of service provision in these cases (Hirvikoski *et al.*, 2016; Schwartzman *et al.*, 2023). An individual with ASD may communicate their needs differently to neurotypical individuals or their ASD may mask the extent of mental health conditions (Cassidy *et al.*, 2018; Smith *et al.*, 2023). Consequently, underdiagnosis of ASD could be problematic (Cassidy *et al.*, 2018; Eyuboglu *et al.*, 2023).

The NCMD (2024) highlights the issue of diagnostic overshadowing in the NHS when treating individuals with LD and/or ASD. This occurs when an individual's physical and/or mental ill-health is misattributed to their disability or condition such as ASD or an individual's ASD overshadows other conditions (NCMD, 2024). For instance, Goldschmidt (2017) provides the example of an individual's response to the physical pain of a broken ankle being attributed to autistic regression. Diagnostic overshadowing can lead to a failure to recognise the interplay of co-morbid conditions, resulting in delays in diagnosis and treatment, mistreatment and increased mortality particularly for individuals with mental illness (Hallyburton, 2022; NCMD, 2024). Despite increasing awareness about this issue, there are a lack of screening tools to identify and assess suicidal ideation and behaviours in people with ASD (Cassidy *et al.*, 2014; Hedley *et al.*, 2017; Horowitz *et al.*, 2018; Schwartzman *et al.*, 2023); connected to this is a lack of practitioner awareness about this issue (Eyuboglu *et al.*, 2023).

The link between ASD and suicide has been identified relatively recently and is under-researched. Further evident is the lack of identification, underdiagnosis and limited provision for people with ASD presenting with suicidal ideation and behaviours. Cassidy and Rodgers (2017) state that a more holistic research approach to this issue could be adopted that considers findings from other studies on suicidology, and also the views of a variety of stakeholders. They further posit that researchers should consider using mixed-methods and/or qualitative approaches when investigating ASD and suicide (Cassidy and Rodgers, 2017). This paper adopts such an approach and consequently provides new knowledge and ways of understanding issues related to ASD, suicide and preventable deaths in health and social care settings in England and Wales.

Methods

This article examines trends identified in inquests in England and Wales for 42 people formally diagnosed with ASD from January 2017 to July 2023, where the death occurred in a health or social care setting. The article does not focus on all deaths linked to ASD during the period 2017–2023, but on publicly available PFDs where the deceased was formally diagnosed with ASD and their death in health or social care was deemed preventable by a Coroner. PFDs from January 2017 onwards were selected as they were considered to align with the publication of the first LeDeR report. PFDs in England and Wales are publicly available from the Judiciary website. As the project uses data in the public domain, no ethical approval was sought.

Relevant PFDs were identified and collected using the Preventable Deaths Tracker website (A platform to learn lessons from coroners' inquests – Preventable Deaths Tracker) using 41 key words and phrases relating to LD that were formulated and agreed upon by the co-authors (Supplementary File 1). These were inputted into the machine-readable version of the Preventable Deaths Tracker database that enables all published PFDs to be reviewed. These identified PFDs were then read by the lead author to eliminate cases where it was overtly clear that the death was not that of a person with LD in a health or social care setting. For example, eliminating cases where someone with LD died in a road traffic accident or in

police custody. A total of 84 deaths were identified, of which 42 were identified as being people diagnosed as having ASD.

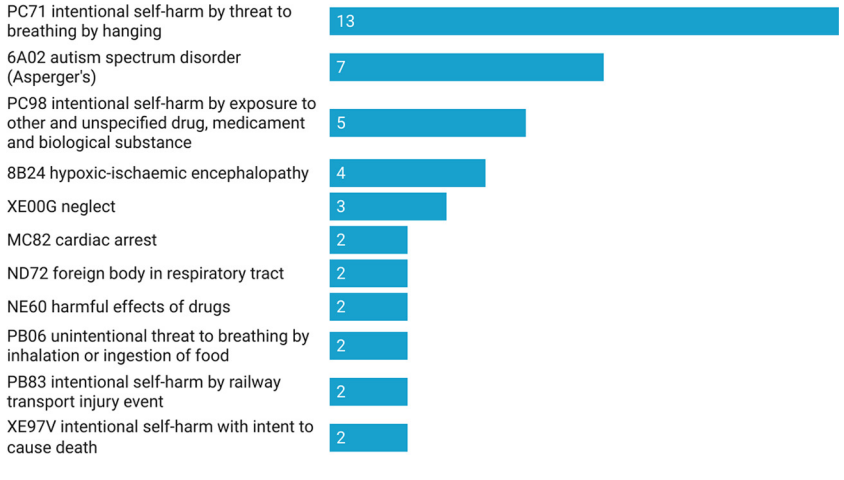
Matrices were constructed to provide a descriptive overview of cases and allowed the researchers to gain familiarity with the data. Matrices included information on age of deceased; sex; the presence of co-morbidities; place of death; conclusion given by Coroner; cause of death as per ICD-11 code. An overview of the data in the matrices is given under the quantitative findings section of this article (see also Supplementary Files 2 and 3 for ICD-11 codes and characteristics of the deceased, respectively). Initial open coding of the PFDs identified broad concepts associated with the circumstances surrounding the deaths. Examples of codes included "autism as a barrier to understanding needs", "failure to recognise risk", "autism as a cause of death" and "lack of local ASD services". Codes were reviewed, which facilitated the identification of recurrent themes associated with the deaths of people with ASD, leading to the emergence of three overarching themes: education and training: inability of staff to recognise and/or understand the complexity of ASD; lack of specialist provision for individuals with autism; death attributed to autism. An inductive approach was adopted to analyse the PFDs, meaning the researchers did not anticipate any specific research findings, rather these emerged from recurrent themes inherent within the data (Bryman, 2012).

Quantitative findings

Of the 42 individuals in the data set, the majority (67%; $n = 28$) died by suicide (Figure 1). Most (50%) suicides were caused by hanging. Coroners either stated an unequivocal conclusion of suicide or the narrative conclusion suggests suicide while the death is instead labelled as "misadventure", for instance. This finding differs from the extant literature by underlining that not all deaths of people with ASD are suicide. The qualitative findings further indicate that even when a conclusion of suicide is reached, Coroners and juries tend to record organisational failings and errors about these deaths.

Figure 1 highlights causes of death using ICD-11 coding (Supplementary File 2). Although presented separately, the codes below were often listed in conjunction with other causes of death and categorised by the researchers as such, reflecting the complex and multicausal

Figure 1 Causes of death, per ICD-11 coding for codes with more than one death



Source: Figure by authors

nature of many deaths investigated by Coroners (Dorries, 2014). For example, if a Coroner recorded a medical cause of "hypoxic brain injury from self-ligature", along with a short-form conclusion of "suicide", this was coded as 8B24 (hypoxic brain injury) and PC71 (intentional self-harm by threat to breathing by hanging).

In 29 deaths (69%), Coroners provided narrative conclusions. Coroners may provide a narrative conclusion instead of, or in addition to, short-form conclusions (e.g. suicide, misadventure, open). Narrative conclusions can vary from one or two sentences in length to several pages. They set out the facts surrounding the death in more detail (e.g. natural causes, contributed to by neglect) (Baker, 2019). The widespread use of narrative conclusions in these cases signals that the circumstances in which many people with ASD die are often complex and multicausal; this is reflected in granular detail in our qualitative findings.

Of the 42 deaths, 60% ($n = 25$) were males. The median age at death was 23 years (IQR: 16–27; $n = 42$), with the youngest death occurring in a four-year-old and the oldest at 61 years.

In addition to ASD, coroners also reported that 21% of the deceased had mental health diagnoses, 10% had ADHD, 7% had depression and 7% had substance abuse/misuse.

Most (64%; $n = 27$) deaths occurred in community settings, followed by acute hospitals (26%; $n = 11$) and psychiatric detention units (10%; $n = 4$).

Thirty-three coroners in 29 coroner areas produced the 42 PFDs. Coroners in Nottinghamshire wrote the most ($n = 4$), followed by Kent Central and Southeast ($n = 3$). Across regions, the South East recorded the most PFDs into deaths of individuals with ASD (Figure 2).

The number of reports published varied over time, with a median of seven reports published each year (IQR: 4.5–8) and the most ($n = 10$) published in 2019 (Figure 3). The reason for variation in PFDs over time and across regions is unknown. These variations highlight the opacity that characterises the Coronial system and by extension, preventable deaths of individuals with ASD. The regional nature of the Coronial system means there is uncertainty about the way deaths are investigated and reported, meaning that data on deaths can be inconsistent and incomplete (Baker *et al.*, 2023).

Qualitative findings

Education and training: inability of staff to recognise and/or understand the complexity of autism spectrum disorder

Fifty-seven percent of PFDs expressed concerns over insufficient understanding of ASD and its connections to comorbid mental health conditions (Cassidy *et al.*, 2014; Hedley *et al.*, 2017). The lack of ASD awareness across agencies acted as a barrier to understanding individuals' mental health needs and, in some cases, led to those requiring mental health support being rejected from services, or being discharged prematurely. In the case below, a lack of training led to an individual's ASD being incorrectly diagnosed by mental health professionals, leading to eventual suicide:

Case 41: Her death was contributed to by the actions and inactions of mental health clinicians entrusted to keep her safe within a care system that was underdeveloped to manage an autistic individual with complex needs.

In this case, the deceased was diagnosed with ASD aged 16 by Child and Adolescent Mental Health Services and her medical records evidenced this. Mental health services, who knew of her ASD, incorrectly attributed it as Emotionally Unstable Personality Disorder (EUPD) instead. The PFD notes this attribution *was not formally diagnosed, and not discussed with [the deceased] who found out by chance when looking at her records.* She

Figure 2 Map of the number of deaths of people with ASD reported in PFDs published in England and Wales: January 2017–July 2023



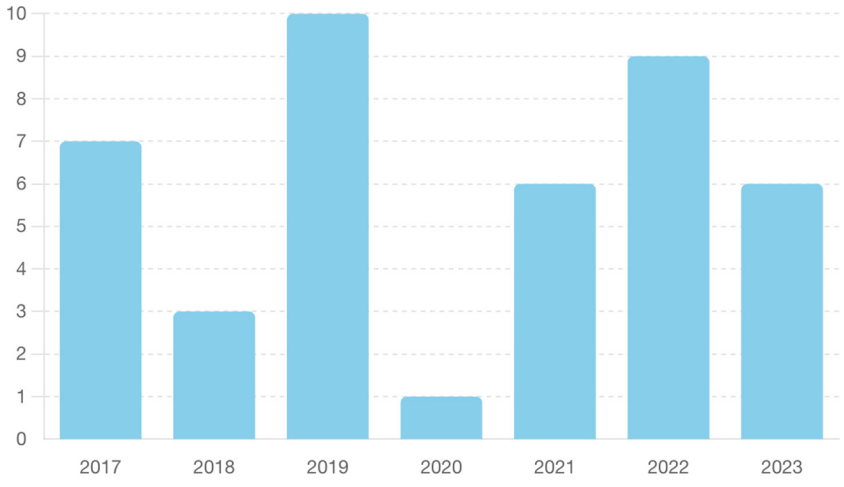
Source: Figure by authors

continued to be treated for EUPD with no reasonable adjustments made regarding her ASD, leading to her withdrawing from services and later suicide (see, for example, NCMD, 2024).

Similarly, Case 37 highlights how a lack of autism training led to professionals overlooking the daily challenges the deceased faced in relation to his ASD (Eyuboglu *et al.*, 2023). He had a history of self-harm and suicidal ideation and was well known to service providers. Throughout his life, there was a lack of understanding of his condition by the agencies involved in his care. This lack of understanding, in addition to poor record keeping, meant he was transferred from a special needs to a mainstream school, which was unable to meet his needs, leading to a period of risk escalation and suicide:

Case 37: The evidence at the inquest revealed a widespread lack of knowledge and understanding of Autism [. . .] the National Autism Strategy does not currently include a

Figure 3 Trends over time of the number of PFDs published in England and Wales involving people with ASD



Source: Figure by authors

timetabled commitment for relevant mandatory Autism training to be provided to all state agencies working directly with autistic adults and children.

The findings under this theme reflect Mencap's (2007) first "Death by Indifference" report, which suggested a widespread lack of understanding and ignorance across the NHS towards individuals with LD (Cassidy *et al.*, 2018). Related to this, the NCMD (2024) note that the issue of diagnostic overshadowing remains an issue within the NHS, meaning that the extent of an individual's mental ill-health may be overlooked and instead attributed to their ASD or their ASD may overshadow other conditions.

Lack of specialist provision for individuals with autism

The lack of understanding and/or training on how to accommodate the needs of individuals with ASD was compounded by a lack of specialist provision (in 38% of PFDs) (Hedley *et al.*, 2017; Hochard *et al.*, 2020). A recurrent theme was that while services may have the capacity to diagnose ASD, they lack the capacity to integrate ASD-related support into care plans, creating a "postcode lottery" of support:

Case 11: Nationally, many trusts only provide a diagnostic service in respect of ASD [. . .] the evidence indicated that some Trusts do provide a service beyond the purely diagnostic but the nature and extent of that service varies depending upon geographical location.

Case 16: The court was advised that CCG [Clinical Commissioning Group] have only commissioned services in respect of the diagnosis of autism and not the management of this condition.

This led to some individuals diagnosed with ASD feeling *hopeless* due to not getting the right support, leading to their disengagement from services with minimal attempts by agencies to follow-up. In other instances, individuals were placed in psychiatric detention units while awaiting a specialist placement. The impact of non-specialist mental health placements on neurodiverse individuals remains largely overlooked in academic literature. However, Williams *et al.* (2023) note a loss of predictability and structure in addition to the sensory environment of non-specialist in-patient mental health settings can exacerbate mental health conditions for individuals with ASD:

Case 10: [The deceased's] distress and stressors before his death included feelings that he was not getting what he saw to be the right help and that he would not lose feelings of helplessness such that he took his own life.

Two cases below highlight the systemic nature of this issue, both males had been diagnosed with ASD and died in the care of the same local authority two years apart:

Case 32: The deceased was diagnosed with ASD, in addition to Prader-Willi Syndrome, a genetic condition associated with behavioural issues. The narrative conclusion was that he: *died as a consequence of injuries sustained during an episode of high-risk behaviour, related to his Prader-Willi syndrome, on a background of inadequate support from the Local Authority and Mental Health Services.* His family struggled to manage his behaviour and repeatedly requested assistance from social services, but no support was forthcoming. The inquest found that: *the way services were managed meant those involved [in his care] had little knowledge of what was available.*

Case 33: The deceased was similarly let down by a lack of local services for autistic children. Following a decline in his mental health, his parents were passed around services in attempts to secure specialist autism-related support for their son: *The service the family approached did not consider [the deceased] was suitable for short-term counselling and advice was given to approach his GP. On 15th March 2022 [the deceased's] Mum spoke to his GP and asked for a letter to apply for funding from specific autism related counselling which his GP did but this was rejected on 17th March 2022 [. . .] On 20th March [the deceased] was found hanging at home.*

Findings from our analysis echo the most recent LeDeR report about deaths of people with ASD; LeDeR similarly highlighted a lack of training, awareness and understanding of the specific needs of autistic people; a lack of specialist services; a lack of awareness of the increased risk of suicide for autistic individuals; and mental health conditions overshadowing the impact of ASD (LeDeR, 2023).

Attributing an individual's autism spectrum disorder as their cause of death

Seven PFDs listed ASD as a medical cause of death, reflecting an early piece of research on ASD and suicide ideation that noted autism was frequently reported as a cause of death (Howlin *et al*., 2005). Of the seven, one death was explicitly recorded as suicide and one death suggested suicide in the circumstances but was recorded as "misadventure". Life expectancy for individuals with ASD is, on average, 16 years less than for the general population (Hirvikoski *et al*., 2016). Yet individuals do not die from ASD; it is a neurological condition that impacts how individuals process information and communicate with others. Listing ASD as a cause of death to some extent masks failures of the agencies involved in the decedent's care. An example of this was Case 39, where the lack of specialist provision was recorded as a key factor contributing to the death, yet the cause of death was attributed to ASD:

Case 39: His Autism led him to follow a restricted diet [. . .] [his] lifestyle probably led to the development of chronic liver disease and a degree of heart failure [. . .] [his] Autism was the root cause of his tragic and untimely death because it prevented him from accessing the medical assistance that he required. There is no specialist service commissioned to provide ASD patients with long term dietetic support, and I heard this is what [the deceased] needed.

Similarly, the cases below highlight ASD as a contributory factor in their deaths despite, in Case 28, failures of the deceased's school to carry out a well-being check, or in Case 19, failure to prepare food in line with their care plan:

Case 28: [The deceased] had learning difficulties and, when his mother died unexpectedly at home [. . .] he did not know how to call for help or feed himself properly. He died a fortnight later of dehydration and starvation.

Case 19: [The deceased] choked on food given to her by carers [. . .] On the basis of evidence from the speech and language therapist [. . .].It was found that [she] was fed high risk foods for at least 3 months by carers at the home. There was evidence staff were unaware of the extent of the eating plan.

The attribution of ASD as a cause of death can be seen as an example of what might be termed "the social construction of death" (Prior, 1989). In this reading, Coroners attempt to create order by organising the complex events that lead to individuals' deaths into a comprehensible narrative (Baker, 2019). The discretion afforded to Coroners and the factors influencing their construction of narratives are complex, but can be influenced by institutional structures, social norms and evaluative judgements of the deceased (Baker *et al.*, 2023). These narratives in particular highlight the importance of reflecting on judgements made about an individual's ASD and/or health conditions, something that Mencap (2007, p. 2) identified as professionals having a "lazy fatalism that these groups just do die younger".

Discussion

By using Coronial data, this article demonstrates that the deaths of people with ASD are not all suicides, making an original and important contribution to knowledge on this issue; and that there are significant organisational failings that lead to such deaths. Previous research into PFDs in health-care settings also highlighted similar structural failings, for example, Bremner *et al.* (2023) provide a systematic review of PFDs in relation to patient safety. Regarding health-care deaths, they noted concerns around communication, lack of skills/knowledge, uncoordinated care and lack of resources.

It is more than 15 years since the publication of Mencap's (2007) "Death by Indifference" report. The authors of this article argue that indifference remains at the heart of understanding the extent and nature of deaths of people with ASD. Indifference can be seen in both service provision and death investigation. Tester (2002) describes indifference as a lack of concern or disinterest towards individuals experiencing suffering. Both the causes and consequences of indifference have been examined in relation to, but not exclusively, genocide and mass violence (Bauman, 1990; Herzfeld, 1992), harms caused by corporations (Pemberton, 2004) and societal indifference towards harms experienced by prisoners (De Vel-Palumbo and Berryessa, 2023). Basaran (2015, p. 206) notes that indifference towards harm occurs as a result of wider political and social contexts and their potential to produce states of what they term "collective indifference".

In this sense, the indifference seen in service provision is not separable from the political and economic context of the UK. In using the term indifference, the authors are not arguing that staff intended to cause harm. The introduction of austerity measures following the 2008 financial crisis led to significant funding cuts in the health and social care sector that have progressively eroded the resilience and compassion of staff who are increasingly expected to do more with less (Hernandez, 2021). The findings demonstrate the need for staff to remain professionally curious, meaning to not act on assumptions and demonstrate a willingness to engage with individuals with ASD and understand their circumstances. The chronic underfunding of services, however, acts as a barrier to professionals having the time and emotional capacity to engage with individuals in this way. For example, writing about the maltreatment of older people in health and social care in the UK, Galpin (2012) notes that high caseloads and pressures facing professionals can reinforce attitudes of indifference and cause them to become detached from clients' needs.

The political and moral exclusion of certain groups works to foster their invisibility, producing a lack of concern when their rights are undermined (Passini, 2017). The exclusion of those with ASD is manifest in the lack of data on health inequalities experienced by these individuals. It is not clear why deaths of people with ASD were not

directly addressed in LeDeR data until 2022, or why the initial CIPOLD report barely mentions ASD (LeDeR, 2023; Heslop *et al.*, 2013). The resultant invisibility of individuals with ASD can go some way to explaining findings one and two from this article in terms of why their needs were often overlooked and misunderstood by various professionals together with the interlinked issue of lack of specialist provision.

The indifference apparent in how individuals with ASD are treated in health and social care is closely connected to the way their deaths are categorised by Coroners. The state of being indifferent towards suffering carries moral implications and is informed by norms and judgements about which lives are seen as "worthy" of intervention (Basaran, 2015, p. 209; Tester, 2002). The construction of narrative by Coroners, identified in the third theme, reflects the values that were partly causal in the death of the individual. Baker (2016) notes that documents, such as PFDs, are socially constructed and should be considered in relation to the wider social and institutional context in which they are produced. The listing of ASD as a cause of death could be said to be rooted in assumptions about what kind of life an individual with ASD should have and for how long. With LeDeR now beginning to publish data on health inequalities experienced by individuals with ASD, this could be seen as a starting point for breaking the cycle of collective indifference. That said, the extent to which these preventable deaths can be reduced remains questionable given there remains no mandatory requirement to report these deaths to LeDeR, compounded by the lack of national oversight and analysis in the Coronial system (Baker *et al.*, 2023).

The authors note some potential limitations to the data set used in this article. Although 41 key words were formulated and agreed upon by professionals experienced in researching deaths in health and social care, it is possible that varying the key words may have produced a different number of PFDs. Furthermore, in the data gathering process the authors identified no PFDs related to deaths of people with ASD in the North East of England. The lack of PFDs from Coronial districts has also been referenced in other research (Zhang and Richards, 2023). One reason could be that not all PFDs are published on the Judiciary website. There may also be cases that are investigated at inquest, but no PFD is subsequently issued by Coroners, because they did not believe that organisational lessons could have been learned. The utility of PFDs is further complicated by absences on each report; some PFDs in the data set did not note the age of the deceased and ethnicity was not recorded on any PFDs. Despite these limitations, the authors contend that PFDs represent a valuable source of data in relation to deaths of people with ASD, particularly given the lack of research on this issue.

As the majority of extant literature on people with ASD is quantitative in nature, future qualitative research could be undertaken with Coroners and other key stakeholders, such as health professionals, or bereaved family members, to provide a holistic understanding of how deaths of people with ASD are reported, investigated and classified. Organisational responses to PFDs are also under-researched (Baker *et al.*, 2023), and as such there is potential for research to be undertaken on responses to PFDs into deaths of people with ASD and investigate the extent to which Coronial concerns have been addressed.

Conclusion

This article has sought to understand how and why deaths of people with ASD occurred using Coronial data generated between 2017 and 2023, where the death occurred in a health or social care setting. Currently, there is limited research on deaths of people with ASD; the existing literature is mostly quantitative in nature and focuses on ASD and suicide. The findings presented in this article make an initial step in highlighting significant structural failures that lead to preventable deaths of people with ASD. It explores the concept of indifference as one way to understand the extent and nature of these deaths and why progress remains problematic in reducing the number of deaths of people with ASD in

England and Wales. Although the inclusion of deaths of people with ASD by LeDeR may lead to growing awareness of the nature of these deaths, ultimately the lack of a dedicated regulatory agency tasked with investigating these deaths means that this data remains opaque and uncertain, limiting the extent to which lessons can be learned about deaths of people with ASD.

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Supplementary material

The supplementary material for this article can be found online.

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